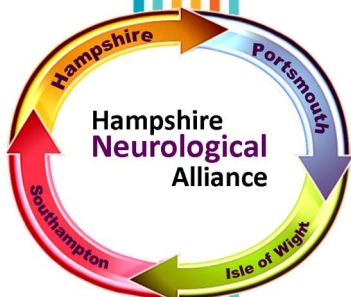




NEUROLOGICAL INFORMATION BOOKLET

Getting the best from
Neurological Services in
Southampton, Hampshire,
Isle of Wight and Portsmouth



A directory of health, social and
community support for people
with long-term neurological
conditions and carers

This directory is for any person living with a neurological condition,
their family and carers

It has been developed as a general resource and
is not intended to replace clinical or medical advice, which
should be provided by your GP and/or healthcare professional.

This directory may also be useful for people working in
health and/or social care organisations or in voluntary organisations
that support or provide services to people
with long-term neurological conditions and their carers.

Please use the contents page on Page 5 to help you
to navigate through the directory

Second Edition - updated March 2018

Foreword

Welcome to the second edition of the Neurological Information Booklet produced by Hampshire Neurological Alliance (HNA).

The Information Booklet aims to:

- List many known neurological conditions
- Identify services available to support people with a neurological condition
- Signpost people to the organisations that can support them
- Help people to find their way around the health and social care systems

It does not claim to have all the answers for everyone. It is an attempt to gather in one document the information, advice and guidance needed by people with neurological conditions in the geographical areas of Southampton, Hampshire, Isle of Wight and Portsmouth. The information will continue to develop and grow and we will need your help to ensure it is comprehensive, accurate and up to date.

We have made every attempt to gather accurate and appropriate information and to ensure the information details in this directory are correct at the time of collation. We hope you will let us know if anything is missing, inaccurate or needs amending. We hope everyone who uses the resource will contribute more information about any local and national resources of which we are currently unaware. Please respond to the link on our website if you are aware of any changes, omissions or alterations needed. www.hampshireneural.org.uk

We anticipate that a number of updates of this booklet will be needed each year, so we are only printing a small number of this edition. A useful complementary signposting leaflet will be available widely throughout the area to raise awareness of this resource. The booklet and leaflet are available from our offices or can be downloaded from our website.

We are grateful to all those people and organisations who have contributed their time, knowledge and expertise to this piece of work. A special thank you goes to Georgiana Robertson and Annette Scivier, who spent many hours reviewing the contents.

We do hope that you find the booklet and leaflet useful.

Best wishes



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Hampshire SO518DE

Our partners in producing the Booklet:
Carers Together
Huntington's Disease Association UK
Motor Neurone Disease Association
Multiple Sclerosis Society
Parkinson's UK
Stroke Association
PSP Association

Hampshire Neurological Alliance (HNA)

Hampshire Neurological Alliance (HNA) is an umbrella organisation for people with long-term neurological conditions (LTNCs) and their carers from a wide geographical area including Hampshire, Isle of Wight, Portsmouth and Southampton. It was set up in 2008. All our trustees are people with long-term neurological condition and/or carers. HNA is constantly developing and changing to meet changing needs and new developments. We work closely with a number of local condition-specific organisations forming a Steering Group to guide and support our actions.

Our Aim

To obtain the best possible care and support for all people who are affected by a neurological condition and their carers.

Our Activities

- We support people with a neurological condition.
- We support carers of people with a neurological condition.
- We work with local service providers and commissioners to secure the best possible care and support for all people in the area affected by a neurological condition.
- We include and represent a wide range of neurological conditions.
- We provide information about services in the area for people with a neurological condition.

Our Members

Members include **people** affected by a neurological condition including carers, families and friends and **organisations** that support people with neurological conditions.

Our Priorities

- To listen to what people with neurological conditions say they need to support them.
- To develop an effective information resource that will support them.
- To be led by our members and those affected by a long-term neurological condition.
- To ensure our members are kept up to date with any changes in legislation that may affect them.
- To reach out to all individuals affected by a long-term neurological condition.
- To encourage people to be as independent as possible with the right information, help & support
- To work in partnership with other organisations that support people with a neurological condition to ensure people are able to access the right information, in the right place and at the right time.
- To work with health and social care to encourage them to provide improved person centred coordinated care.
- To influence equality of access and raising of standards
- To campaign for better provision of key therapeutic services e.g. physiotherapy, occupational therapy, palliative care, pain management, dietary advice and therapeutic massage.
- To continue to campaign to strengthen and broaden the network of specialist nurses for neurological conditions.
- Seek sponsorship and funding to support our work and improve the services we can offer

Benefits of joining HNA

- Access to information
- Meet others at events
- Learn more about new and emerging changes in health and social care.
- Use your personal experience and ideas to influence how local services are run and developed.
- Strengthen the Alliance

Please contact us if you would like to find out more about the Alliance, would like other information or wish to make a constructive comment or suggestion:

Write to: Hampshire Neurological Alliance, 9 Love Lane, Romsey SO51 8DE

Telephone: 07847 794937

Email: contact@hampshireneural.org.uk

Website: www.hampshireneural.org.uk

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Quotes from service users:

*'Patients, service users and carers are not commodities,
they are individual people.'*

'Every individual has different needs, skills and expertise'

How to use this Booklet

This booklet is divided into sections, so you can flick around between them as you wish:

- 1 Health, Social Care and other useful services available to assist you
- 2 General and Frequently Asked Questions with answers and contact links
- 3 Contacts List of National, Regional and Local organisations

Where to Start?

I have recently been diagnosed with a neurological condition. Where can I get specific advice and support?

When you first realise that you have a long-term neurological condition, it can be very confusing and hard to take in what you are told by a doctor.

This booklet gives guidance and information which you may need, both at the start and later during your journey with the condition.

How do you know what you don't know...?

Sometimes you don't know what you don't know.....so you don't ask about it.....nor do you know who to ask to find out..... This can lead to essential information and action being delayed or unavailable to you.

There are three main routes to finding out more:

- a) through formal medical and social care support
- b) through national, regional and local neurological organisations where you can access condition-specific professional support
- c) through local neurological or carer support groups where you can meet others in similar circumstances.

We have tried to set out this information in a clear, easy to access way giving national and local website contacts, telephone numbers and names

It is important to note that this booklet does not replace your essential relationship with any health professionals that support you.

Please ensure you seek professional advice and treatment whenever your condition changes or causes concern.

If there is sudden change or concern about your health or ability call 111 (see page 9).

Please note that sometimes the link may need to be 'copied' and 'pasted' into your browser if 'control click' doesn't work

“We must become the change we want to see.”

*(Mohandas Karamchand Gandhi, aka Mahatma Gandhi, 1869-1948,
Indian statesman and spiritual leader, humanitarian
and constitutional independence reformer)*

1. Introduction

What is a neurological condition?

'A long-term neurological condition results from the disease of, injury or damage to, the body's nervous system (i.e. the brain, spinal cord and or their peripheral nerve conditions which will affect the individual and their family in one way or another for the rest of their life'.¹

Neurological disorders are very common, accounting for about one in ten general practitioner consultations². They affect the brain, spinal cord, peripheral nerves and muscles. They include many different conditions of varying severity, some very common and others exceedingly rare, from migraine, to motor neurone disease.

Despite considerable advances in investigations, diagnosis still relies almost entirely on history and examination, both of which require training, practice and experience to interpret and perfect.

Neurological conditions include:

- Intermittent disorders, such as epilepsy, migraine and other headache problems;
- Progressive long-term condition, such as Parkinson's, multiple sclerosis (MS) and dementia;
- Life-threatening acute (or suddenly occurring) conditions, such as stroke, meningitis, encephalitis, status epilepticus, acute inflammatory neuropathies, traumatic brain injury and subarachnoid haemorrhage;
- Hereditary neurological diseases such as Huntington's.

They are very common in the UK:

- Neurology symptoms account for 20% of acute hospital admissions and are the third most common reason for seeing a GP
- 0.6-1% of the population is diagnosed with a neurological condition every year and 1 in 6 people have a neurological condition that makes a significant impact on their lives
- 2% of the UK population are disabled by a neurological condition and 850,000 people are caring for someone with a neurological condition³
- The lifetime prevalence of both MS and Parkinson's is 2 per 1,000 population and double that for active epilepsy
- The lifetime prevalence of headache is 90%, and for young women it is the most common symptom reported in the community⁴

1 in 7 people in any area are affected by a long-term neurological condition (LTNC).

In Southampton, Hampshire, Isle of Wight and Portsmouth there are approximately 285,000 people affected by a long-term neurological condition. This includes:

Hampshire	(approx. 200,000)
Isle of Wight	(approx. 20,000)
Portsmouth	(approx. 30,000)
Southampton	(approx. 35,000)

1 in 6 people are carers and approximately 80% of those are affected by a LTNC.

¹ Department of Health (2005) National Service Framework (NSF) for Long-Term Conditions

² Department of Health (2005) National Service Framework (NSF) for Long-Term Conditions

³ Department of Health (2005) National Service Framework (NSF) for Long-Term Conditions

⁴ 'Local adult neurology services for the next decade: report of a working party', Royal College of Physicians, and Association of British Neurologists, June 2011

Quotes from service users and carers:

'Anyone with a disability, long-term health condition or illness is a person first.'

Planning and support for any person should be holistic and person-centred and mean a person's needs are met as an individual and as someone with a disability, long-term health condition or illness'.

'A carer is a person first. Planning and support for any carer should be holistic, person-centred and mean a carer's needs are met as an individual and as a carer'.

2. Neurology Generic Care Pathway

A 'care pathway' is a useful tool to guide and map the care you receive, by whom and at what stage in your condition.

Early symptoms

GP, Consultant Neurologist / Physician / Geriatrician (in a GP surgery or Consultant Clinic). Examination and tests leading to diagnosis, and signposting to education and support.

Early stage management

GP, Consultant Neurologist / Physician / Geriatrician, Specialist Nurse, Therapist, Neurology Care Advisor (in clinics and various health care settings).
Education and optimising symptom management and supported self-care.

Middle stage management

GP, Consultant Neurologist / Physician / Specialist Nurse, Community Nurse, Therapist, Neurology Care Advisor, Adult Care and Support and other agencies involved in support (in clinics and various health and social care settings or own home).
Condition management with supported personal health and care plans to enable health, independence and well-being. Supported self-care and access to assistive technology.

Complex stage management

GP, Consultant Neurologist / Physician / Specialist Nurse, Community Nurse, Palliative Care Service, Therapist, Neurology Care Advisor, Adult Care and Support and other agencies involved in support (in clinics and various health and social care settings or own home).
Access to specialist support and care as needed as close to home as appropriate.

Keeping you informed

Your consultant and GP should be able to provide you with comprehensive information about your condition. If you are under the care of a specialist nursing team, or a health/social care professional, they will also be able to provide information, or direct you to a reliable source.

In addition most neurological conditions have a national organisation that represents the interests of people living with, and affected by that condition.

At the back of this directory are comprehensive contact details for each of these groups.

Quote from a service user:

‘As service users and carers it is easy to spot three kinds of professional from all parts of health and social care including commissioners and providers:

- those who care but think they know best
- those who listen but only enact what they agree with and
- those who engage with service users on an equal footing, using expertise on both sides to co-design services and achieve better outcomes.’

3. Primary and Secondary Health Care and Clinical Services

a. Clinical Commissioning Groups (CCGs)

Clinical Commissioning Groups (CCGs) were set up by the Health and Social Care Act in 2012. They replaced Primary Care Trusts on 1 April 2013. They are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. There are now 195 CCGs in England. They are clinically led by GPs (and other staff who work with patients) and are best placed to make decisions about local healthcare commissioning.

Fareham and Gosport CCG	www.farehamandgosportccg.nhs.uk/
Isle of Wight CCG	www.isleofwightccg.nhs.uk/
North East Hants and Farnham CCG	www.northeasthampshireandfarnhamccg.nhs.uk/
North Hants CCG	www.northhampshireccg.com/
Portsmouth CCG	www.portsmouthccg.nhs.uk/
South East Hants CCG	www.southeasternhampshireccg.nhs.uk/
Southampton CCG	www.southamptoncityccg.nhs.uk/
West Hants CCG	www.westhampshireccg.nhs.uk/

b. Provider Trusts

It can be quite difficult to understand how health organisations are structured and who does what in the services, so below we list the current major health provider trusts and hospitals.

There are many organisations which offer excellent care for those with Long-term Neurological Conditions across Hampshire and the Isle of Wight but whose contracts with CCGs and Hospital Trusts frequently change.

Therefore this list will change and adjust as time goes on and you should check back regularly for up-to-date information.

[If you have any information to share, add or remove please let us know.](#)

Solent NHS Trust

Services can be found around various NHS locations in Southampton and Portsmouth (and surrounding districts), the administrative and managerial centre is based in Southampton at: Adelaide Health Centre, Western Community Hospital Campus, William Macleod Way, Millbrook, Southampton SO16 4XE Tel: 023 8060 8900 (Central Office)

www.solent.nhs.uk/page.asp?fldArea=1&fldMenu=1&fldSubMenu=0&fldKey=14

Solent NHS Trust provides community and mental health service. They are the main provider of community services to people living in Portsmouth, Southampton and in parts of Hampshire, and also the main provider of mental health services to people living in Portsmouth.

Solent NHS Trust services are organised into eight service lines. Each service line is led by a clinician and supported by a senior operational manager. This structure gives clinicians a leading role in the development, performance and quality of their services.

These eight service lines are:

- Adult Services, Portsmouth
- Child and Family Services
- Adult Services, Southampton
- Sexual Health Services
- Primary Care and Long-term Condition Services
- Substance Misuse Services
- Adult Mental Health Services
- Specialist Dental Services

Southern Health NHS Trust

Southern Health NHS Foundation Trust, Tatchbury Mount, Calmore, Southampton, SO40 2RZ
Southern Health provides community health, mental health, learning disability and social care services across a wide geographical region from Southampton to Oxford.

www.southernhealth.nhs.uk/services/find/

Southern Health manages a number of Community Hospitals shown below.

Community Hospitals

Alton Community Hospital

Chawton Park Road, Alton, Hampshire GU34 1RJ Tel: 030 0003 2196

Fareham Community Hospital

Brook Lane, Sarisbury, Southampton SO31 7DQ Tel: 01489 587400

Fleet Community Hospital

Church Road, Fleet, Hampshire GU51 4LZ Tel: 01252 813800

Fordingbridge Hospital

Bartons Road, Fordingbridge, Hampshire SP6 1JD Tel: 01425 652255

Gosport War Memorial Hospital

Bury Road, Gosport, Hampshire PO12 3PW Tel: 023 9252 4611

Hythe Hospital

Beaulieu Road, Hythe, Hampshire SO45 4ZB Tel: 02380 846046

Lymington New Forest Hospital

Wellworthy Road, Lymington, Hampshire SO41 8QD Tel: 01590 663000

Milford-on-Sea War Memorial Hospital

Sea Road, Milford-on-Sea, Lymington SO41 0PG Tel: 01590 648100

Petersfield Hospital

Swan Street, Petersfield GU52 3LB Tel: 023 8231 9000

Romsey Hospital

Winchester Rd, Romsey, Hampshire SO51 7ZA Tel: 023 8231 0350

Community Neurological Rehabilitation Team (CNRT) is based at The Western Hospital

Tel: 023 8029 6223

Snowdon Neuro Rehabilitation Centre

is based at The Western Hospital

Tel: 023 8069 8401

c. Hospital Trusts and Hospitals

Hampshire Hospitals NHS Foundation Trust

Hampshire Hospitals NHS Foundation Trust serves a population of approximately 600,000 across Hampshire and parts of West Berkshire. This includes Andover, Basingstoke, Eastleigh and Winchester, surrounding towns and villages across Hampshire and parts of West Berkshire including Tadley to the north; Alton and Bordon to the east; Romsey and Chandlers Ford to the south, plus Stockbridge, Bishops Waltham and Alresford.

Clinical services are organised into three divisions.

These are: [Surgical Services](#), [Medical Services](#) and [Family and Clinical Support Services](#)

The Trust covers hospitals in Andover, Basingstoke and Winchester and several smaller hospitals connected with these.

www.hampshirehospitals.nhs.uk/

Andover War Memorial Hospital Tel: 01264 358811 or 01962 863535

Charlton Road, Andover, Hampshire SP10 3LB [Andover War Memorial Hospital](#)

Services include Minor Injuries Unit and Day hospital, Day Surgery, Diagnostic Imaging, Inpatient, Outpatients, Pharmacy, Phlebotomy (blood tests), Podiatry, Rehabilitation

Minor Injuries Tel 01264 835218

Basingstoke & North Hants Hospital Tel: 01256 473202

Aldermaston Road, Basingstoke, RG24 9NA

[Basingstoke and North Hampshire Hospital](#)

Basingstoke and North Hampshire Hospital has around 450 beds and provides a full range of planned and emergency services. These include specialist services for rare or complex illnesses for patients across the UK, including liver cancer, colorectal cancer and pseudomyxoma peritonei (a rare lower abdominal cancer). The regional haemophilia service is based here in this hospital and also purpose built diagnosis and treatment centre (DTC).

Royal Hants County Hospital (RHCH) Tel: 01962 863535

Romsey Road, Winchester, Hampshire SO22 5DG [Royal Hampshire County Hospital](#)

Royal Hampshire County Hospital provides a full range of general hospital services including accident and emergency, general and specialist surgery, general medicine, intensive care, rehabilitation, chemotherapy, diagnostic services, out-patient clinics, paediatric care.

The site also houses **Florence Portal House** (which provides maternity, neonatal, breast screening and some gynaecology services) and an education centre.

Isle of Wight NHS Trust

St Mary's Hospital Parkhurst Road, Newport, PO30 5TG Tel: 01983 524081 www.iow.nhs.uk

Ryde Community Clinic 70-71 Swanmore Road, Ryde, PO33 2TF Tel: 01983 563355

Woodlands 49 Mary Rose Avenue, Wootton Bridge, Ryde PO33 4LP Tel: 01986 552451

Portsmouth Hospitals NHS Trust

Portsmouth Hospitals NHS Trust provides a wide range of inpatient and outpatient healthcare services, serving a population of 550,000 in Portsmouth, Gosport and the surrounding area of South East Hampshire. The Trust provides a range of acute and specialist healthcare services to over half a million patients each year and we are able to develop services which meet the needs of our patients at different stages of their treatment and care.

There is one major site currently owned and run by the Trust: www.porthosp.nhs.uk

Queen Alexandra Hospital, Southwick Hill Road, Cosham, PO6 3LY Tel: 023 9228 6000

There are peripheral community sites for Outpatient Activity in: St Mary's NHS Treatment Centre, Portsmouth and in Petersfield, Emsworth, Havant, Gosport and Fareham.

www.uhs.nhs.uk/AboutTheTrust/AboutTheTrust.aspx

University Hospital Southampton NHS Foundation Trust provides services to people living in Southampton and south Hampshire, plus specialist services such as neurosciences, cardiac services and children's intensive care to people in central southern England and the Channel Islands. The Trust is also a major centre for teaching and research in association with the University of Southampton and partners including the Medical Research Council and Wellcome Trust. The Trust has several hospitals:

Wessex Neurological Centre provides treatment for disorders affecting the brain, spine and nerves. <http://www.uhs.nhs.uk/OurServices/Brainspineandneuromuscular/Brainspineandneuromuscular.aspx>

Southampton General Tel: 023 8077 7222

Tremona Road, Southampton, Hampshire SO16 6YD

www.uhs.nhs.uk/Ourhospitals/SGH/SouthamptonGeneralHospital.aspx

Southampton General Hospital is a large teaching hospital and provides specialist expertise to the South of England region. It houses renowned centres of excellence in the treatment of cancer, heart disease, respiratory illness, neurological disease, gastro-intestinal conditions and illnesses affecting children.

Countess Mountbatten House Tel: 023 8047 7414

Moorgreen Hospital, Botley Road, West End, Southampton, Hampshire SO30 3JB
<http://www.uhs.nhs.uk/Ourhospitals/CMH/CountessMountbattenHouse.aspx>

Countess Mountbatten House (CMH) is a regional NHS palliative care service. It is set in attractive gardens on the east of Southampton and provides a specialist palliative (end of life) care service for patients with advancing cancer, and their families, providing all levels of care.

Princess Anne Hospital Tel: 023 8077 7222

Coxford Road, Southampton SO16 5YA

NB. The middle section of all direct-dial phone numbers has changed from 8079 to **8120**. For example, 023 8079 8773 is now 023 **8120** 8773.

Princess Anne is a centre of excellence for maternity care, providing a comprehensive service. Other services at the Hospital include genetics and breast screening

New Forest Birth Centre Tel: 023 8074 7690

New Forest Birth Centre, Ashurst Hospital, Lyndhurst Road, Ashurst, Southampton SO40 7AR

Royal South Hants Tel: 023 8063 4288

Brintons Terrace, Southampton, Hampshire SO14 0YG

Southampton Children's Hospital Tel: 023 8077 7222

Southampton General Hospital, Tremona Road, Southampton SO16 6YD

<http://www.uhs.nhs.uk/Ourhospitals/SCH/SouthamptonChildrensHospital.aspx>

Southampton Children's Hospital is one of the UK's leading children's hospitals. It is a major centre for specialist paediatric services in the south of England, providing acute specialist care not only to our local population in Southampton but for a much larger area, including the Isle of Wight and the Channel Islands. Specialist paediatric consultants, nurses and wider healthcare teams offer a wide range of diagnosis, treatment and support facilities for children and their parents.

d. Private Hospitals and Hospices

Private Hospitals

The Nuffield Health Wessex Hospital (Chandlers Ford) Tel: 023 8098 6450

Winchester Road, Chandler's Ford, Eastleigh, Hampshire SO53 2DW

www.nuffieldhealth.com/hospitals/wessex

Nuffield Health have brought together private hospitals, health clinics, Fitness & Wellbeing Centres, diagnostic units and a wide range of treatments into one complete healthcare service.

The Spire (Chalybeate Southampton) Hospital Tel: 023 8077 5544

Chalybeate Close, Tremona Road, Southampton, SO16 6UY

www.spirehealthcare.com/southampton/

The Spire Portsmouth Hospital Tel: 0845 606 0325

Durrants Road, Portsmouth PO9 5NP <http://www.spirehealthcare.com/portsmouth/>

Sarum Road Hospital Tel: 01962 844555

Sarum Road, Winchester, Hampshire SO22 5HA

<https://www.bmihealthcare.co.uk/hospitals/bmi-sarum-road-hospital>

BMI The Hampshire Clinic Tel 01256 357111

Basing Road, Old Basing, Basingstoke RG24 7AL

<https://www.bmihealthcare.co.uk/hospitals/bmi-the-hampshire-clinic>

St Mary's Hospital - Mottistone Suite Tel: 01983 526699

Parkstone Road, Isle of Wight PO30 5TG www.themottistone.co.uk

Wessex Skin Clinic Ltd

9-10 Norman Road, Winchester SO23 9PW Tel: 01962 879961

<http://wessexskin.com/>

Optegra Solent Eye Hospital Tel: 0808 250 8585

Fusion 3, Solent Business Park, 1200 Parkway, Whiteley, Hampshire PO15 7AD

www.optegra.com/

Priory Hospital Southampton

Hythe Road, Marchwood, Southampton, Hampshire SO40 4WU SatNav postcode: SO40 4DA

Tel. 023 8084 0044

Website: www.priorygroup.com

Hospices

John Cheverton Centre Tel: 01983 529511

Earl Mountbatten Hospice, Halberry Lane, Newport, Isle of Wight PO30 2ER

<http://www.iwhospice.org/>

The Rowans Hospice Tel: 023 9225 0001

Purbrook Heath Road, Purbrook, Waterlooville, Hampshire PO7 5RU

info@rowanshospice.co.uk <https://www.rowanshospice.co.uk/index.php?id=1>

St. Michael's Hospice (North Hampshire) Tel: 01256 844744

Basil de Ferranti House, Aldermaston Road, Basingstoke, Hampshire RG24 9NB

info@stmichaelsospice.org.uk <https://www.stmichaelsospice.org.uk/about-us.html>

Naomi House Childrens Hospice and Jack's Place Tel: 01962 843513

Stockbridge Road, Sutton Scotney, Winchester, Hampshire SO21 3JE

www.naomihouse.org.uk/

Countess of Brecknock Hospice Tel: 01264 835288

Charlton Road, Andover, Hampshire SP10 3LB <http://www.countessofbrecknockhospice.co.uk/>

Oakhaven Hospice Tel: 01590 670346

Lower Pennington Lane, Lymington SO41 8ZZ www.oakhavenhospice.co.uk/

4. Neurological Services and Health Management

a. General Practitioner (GP)

A GP is a doctor who has specialised in general practice and is based in a local surgery or Health Centre. Once you are registered with a GP this is the single point of access for referral to all other health and social care services. Early assessment and diagnosis is crucial in identifying the right treatment and support for people with diseases and disorders of the nervous system. A GP will be able to manage common symptoms such as infections but will often refer on to a consultant or specialist healthcare professional allied to medicine like a specialist nurse or physiotherapist for more complex symptoms like spasticity.

b. Neurology Department and Consultants in Neurology

A Neurologist is a doctor who has specialist knowledge and experience in diagnosis and management of diseases and disorders of the nervous system. Consultants are based centrally in Southampton at the Wessex Neurological Centre, visiting other general hospitals around the region. They run general neurology clinics, where they focus on assessment and diagnosis of fairly common symptoms and conditions, and also more specialist clinics, often run in conjunction with specialist nurses, where the focus is on more complex cases and rarer conditions which demand different expertise. Neurologists work closely with other specialist services such as Stroke Services, Dementia Services and Rehabilitation teams.

Wessex Neurological Centre

- Wessex Brain and Spine Unit, University of Southampton Hospital Trust
www.uhs.nhs.uk/OurServices/Brainspineandneuromuscular/Brainspineandneuromuscular.aspx
- Wessex Neuromuscular Services aka WERMANS (Wessex Regional Muscle and Nerve Service) Tel: 023 8077 7222
[www.uhs.nhs.uk > Our services > Brain, spine and neuromuscular
http://www.uhs.nhs.uk/OurServices/Brainspineandneuromuscular/NeuromuscularWERMANS/Neuromuscular.aspx](http://www.uhs.nhs.uk/OurServices/Brainspineandneuromuscular/NeuromuscularWERMANS/Neuromuscular.aspx)

c. Neurosurgery Service and Consultant Neurosurgeons

Your GP can state your choice when you are referred, or alternatively this may be possible via the 'Choose and Book' system. Surgery is provided centrally at the Wessex Neurological Centre, and depending on clinical need, occasionally at other specialist tertiary centres outside the Wessex Centre.

<http://www.uhs.nhs.uk/OurServices/Brainspineandneuromuscular/Neurology/Neurology.aspx>

For enquiries about an admission, appointment, operation date or to let us know of any changes to arrangements please telephone:

Southampton neurology office: 023 8120 8998

Portsmouth neurology office: 023 8120 4922 (enquiries regarding appointments for neurology patients seen at [Queen Alexandra Hospital, Portsmouth](#))

Portsmouth NHS Trust neurology office: 02392 286000 Ext 3909 or 3910 (023 8120 4922)

Isle of Wight neurology office: 023 8120 6467

Neurology Department at St Mary's Hospital, IOW: 01983 552106

Neurosurgery: 023 8120 6067

d. Specialist Nurses

A specialist nurse is a qualified nurse who has achieved a specialist level of knowledge, experience and skill in a specific condition or area of health management. The specialist nurse is often the clinical lead for the service that helps to manage the symptoms and effects of the condition throughout the care pathway.

Special nurses and coordinators University Hospital Southampton NHS Contacts:

Multiple Sclerosis Tel: 023 8120 6864

Carrie Day, lead multiple sclerosis specialist nurse

Lesley Kempson, multiple sclerosis specialist nurse

Carlene Ford, multiple sclerosis infusion nurse

Epilepsy Tel: 023 8120 8623 epilepsysupport@uhs.nhs.uk

Sara Kerley, epilepsy specialist nurse
Rebecca Case, epilepsy specialist nurse

Myasthenia gravis Tel: 07747 473769 myasthenia@uhs.nhs.uk

Lisa Joyce, myasthenia gravis specialist nurse (Hants IOW, Dorset + Channel Islands)

Parkinson's disease Tel: 023 8029 6214

Anne Martin, Parkinson's disease specialist nurse

Motor Neurone disease Tel: 023 8120 6544

Clare Erridge, motor neurone disease co-ordinator

Stroke Tel: 023 8077 7222

Tracey-Jane Bailey, lead stroke specialist nurse

Huntington's Disease and Younger Onset Dementia Tel: 07824 607 242

Fiona Chaabane Clinical Coordinator for Huntington's Disease and Younger Onset Dementia' E-mail: Fiona.chaabane@uhs.nhs.u

Head Injuries

Head Injury NHS Nurse Specialist in Southampton Miranda.Gardner@uhs.nhs.uk

There are also Specialist Nurses based at Basingstoke, Winchester and Portsmouth, also visiting other centres.

e. **Neuro-rehabilitation Therapy Service**

At the time of the publication of this information booklet, neuro-rehabilitation is provided at:

Southampton, Western Hospital, (Solent NHS Trust) (Snowdon House)

Portsmouth, Queen Alexandra Hospital (Phoenix Rehabilitation Centre, Portsmouth Hospitals NHS Trust) and St Marys Hospital Portsmouth (Solent NHS Trust)

Isle of Wight NHS Trust coordinates all rehabilitation via Single Point Access, Referral, Review & Co-ordination Service (SPARRCS)

Should a specialist assessment be required, the following referral criteria apply:

- Extensive physical impairment with or without tonal management problems
- Marked perceptual and or proprioceptive problems
- Cognitive impairment that impacts on therapy
- Balance problems associated with dizziness or altered neurology
- Where pain is having a significant impact on therapy or recovery
- Complex communication needs that impact on therapeutic handling
- Challenging social issues that impact on the patient's home environment or family unit
- Where the residual effects of the stroke or neurological disability impacts on the patient's future needs/plans (e.g. return to work, further rehabilitation needs)
- Complex positioning and postural difficulties
- Complex situations where rehabilitation potential is uncertain
- Specialist vocational rehabilitation needs
- Unclear rehabilitation potential

Hobbs Rehabilitation is an independent provider of specialist neurological rehabilitation services. It provides a patient-centred neuro-rehabilitation service, including neuro physiotherapy. Find out more at: www.hobbsrehabilitation.co.uk Tel 01962 779796

They have treatment centres at Winchester, Liss, Romsey, Lambourne, Enham near Andover, Lymington, Salisbury and Shepton Mallet.

5. Other Useful Services

a. Carer Support Services

Please remember – you do not need to live with a person to be their carer.

Many organisations that provide support to patients and service users also provide some support to their families and carers.

There are a number of organisations that provide carers support. Some are shown below.

Carers Together

9 Love Lane, Romsey SO51 8DE Tel: 01794 519495

www.carerstogether.org.uk/ Email: admin@carerstogether.org.uk

Carers Together is carer-led and provides support to carers in Hampshire, Portsmouth and Southampton.

Hampshire www3.hants.gov.uk/adult-services/carechoice/carers.htm

Isle of Wight:

Isle of Wight - Carers Support IoW Tel: 01983 533173

www.carersiw.org.uk.

Isle Help, 7 High Street, Newport, Isle of Wight PO30 1UD.Tel: 03444 111 444

www.islehelp.org.uk.

Portsmouth Carers Centre Tel: 023 9285 1864

117 Orchard Rd, Southsea PO4 0AD www.portsmouth.gov.uk/ext/health-and-care/carers/portsmouth-carers-centre

Princess Royal Trust for Carers Tel: 01264 835246

<https://www.carers.org/local-service/winchester> www.carercentre.com

Andover War Memorial Hospital Charlton Road, Andover, Hampshire SP10 3LB

b. Community Nursing Services (District Nurses, Matrons)

If you need nursing care or support at home, a community district nurse could help. District nurses work with community nurses in the primary health care team. They visit people in their own homes or in residential care homes, providing care for patients and supporting family members.

As well as providing direct patient care, district nurses also have a teaching role, working with patients to enable them to care for themselves or with family members teaching them how to give care to their relatives.

Community Nurses (District nurses) play a vital role in keeping hospital admissions and re-admissions to a minimum and ensuring that patients can return to their own homes as soon as possible. They assess the health care needs of patients and families, monitor the quality of care they are receiving and are professionally accountable for delivery of care. They may visit individuals of any age, but often many of them will be elderly, while others may have been recently discharged from hospital, be terminally ill or have physical disabilities.

They may visit patients every day or more than once a day, offering help, advice and support.

They may work on their own or with other groups, such as social services, voluntary agencies and other NHS organisations and help to provide and co-ordinate a wide range of care services.

Community nurses also look after people whose health may be particularly vulnerable, such as older people, children, or people with learning disabilities.

They visit people at home to provide health care: for example, changing dressings or giving injections. They can also help people get any home nursing aids and equipment they need.

Community nurses can provide help and advice on a wide range of health issues. They may also teach families and carers basic care giving-skills.

Community nurses work closely with GPs, local social services and hospitals. Your GP can refer you to a community nursing service. If you are leaving hospital, the hospital may arrange for a community nurse to visit you regularly as part of your 'continuing care' arrangements.

Community Matrons

Community matrons see patients in their own home and in other community settings. They work as part of multi-professional and multi-agency teams. They are highly experienced, senior nurses who work closely with patients (mainly those with a serious long-term condition or complex range of conditions) in a community setting to directly provide, plan and organise their care.

As well as providing nursing care, community matrons act as a 'case manager' – a single point of contact for care, support or advice, typically for a caseload of around 50 very high intensity users. Community matrons see patients in their own home and in other community settings. They work as part of multi-professional and multi-agency teams.

Community matrons are usually deemed to be working as advanced nurse practitioners - highly skilled nurses who can:

- take a comprehensive patient history;
- carry out physical examinations;
- use their expert knowledge and clinical judgement to identify a potential diagnosis;
- refer patients for investigations;
- where appropriate make a final diagnosis;
- decide on and carry out treatment, including the prescribing of medicines, or refer patients to an appropriate specialist;
- use their extensive practice experience to plan and provide skilled and competent care that meets patients' health and social care needs, involving other members of the healthcare team as appropriate;
- ensure the provision of continuity of care, including follow-up visits;
- assess and evaluate, with patients, the effectiveness of the treatment and care provided, making changes as needed;
- work independently, although often as part of a healthcare team;
- provide leadership;
- make sure that each patient's treatment and care is based on best practice

c. Contenance Services - Specialist

The Bladder and Bowel Specialist Service provides professional advice, guidance and information on the promotion and management of continence; and facilitates best practice in continence care for faecal and urinary incontinence, including enuresis, and related bladder and bowel problems for children, young people and adults.

Solent NHS Trust operates a continence advisory service that aims to promote continence and the management of incontinence. The service is provided to people resident in their own home, in care homes and in clinic settings. The aim of the service is to promote continence using treatment plans, where possible to improve or cure incontinence and promote independence. Where this is not possible, patients are encouraged to manage their incontinence with the use of correct appliances and products. Referrals are open to any individual who has a GP within Southampton City and some parts of South West Hampshire.

Contenance Advisory Service

Solent Health see website for locations www.solent.nhs.uk/services

Portsmouth Tel: 0300 123 3386 Email: snhs.BladderandBowelPortsmouth@nhs.net

Southampton Tel: 0300 123 3795 Email: snhs.BladderandBowelWest@nhs.net

Southern Health NHS Trust Tel: 01489 587436

IoW Contenance Services - are accessed via the Community Nurses of the IoW NHS Trust

Can I receive free continence aids?

Free continence products (pads) are available (if clinically appropriate) following individual continence assessment. A nurse will do the assessments in your home or in a clinic setting.

NHS www.nhs.uk/Livewell/incontinence/Pages/Incontinenceproducts.aspx

Age UK have details

www.ageuk.org.uk/products/mobility-and-independence-at-home/incontinence-products/

d. Crisis Response Teams

These are multidisciplinary teams designed to respond promptly to a crisis, until a longer-term solution can be put into place. The teams may enable a swift discharge from hospital, or prevent an admission, by putting into place appropriate support and advising how to get longer term help.

Hampshire

Community Response Team (CRT) from Hampshire County Council Adult Services.

The Community Response Team provides short term assessment and re-ablement to help you regain your independence and can carry on living at home for as long as possible. It supports adults over the age of 18 with physical disabilities, mental health problems and older persons.

Firstly they assess your needs to see how to help you regain your independence.

Then you will need to be assessed to see if you meet the eligibility criteria.

The Community Response Team will work with you for a maximum of six weeks. Longer term care packages will be provided by an independent agency if this is identified as a need following a re-assessment by a care manager.

They will help with:

- Promoting Independence: we will help you become more independent in activities such as personal care and daily living tasks
- Personal Care: this could include assisting you with maintaining personal hygiene and skin care
- Health: we will help with health related tasks such as handling of medication
- Well-being: we can assist with maintaining mobility, and social interaction and daily living tasks
- Food and Nutrition: this could include assisting with meal preparation

www3.hants.gov.uk/adult-services/adultservices-professionals/aboutas/structure/community-response.htm

Isle of Wight

Crisis Response Service (CRS) is accessed on the Isle of Wight via a GP referral and NHS 111 in conjunction with SPARRCS www.iow.nhs.uk/our-services/

Portsmouth

Portsmouth Rehabilitation and Reablement Team (PRRT). Contact Trudie Hatchard Tel: 023 8060 8900 ext 3770, 3771 <http://www.solent.nhs.uk/service-info.asp?id=91&utype=1>

Southampton

Rapid Response Team (RRT). Contact Annette Robbins Tel: 02380 716724
www.solent.nhs.uk/service-info.asp?id=83&utype=

e. Dementia Services

The word 'dementia' describes a set of symptoms that may include: memory loss, difficulties with thinking, problem-solving or language. Under the heading 'dementia' there is a range of conditions. The most common are Alzheimer's disease, Vascular dementia, Lewy Body disease.

Dementia is caused when the brain is damaged by diseases (e.g. Alzheimer's disease) or a series of strokes or can be associated with other conditions such as Parkinson's disease or Down's Syndrome.

Dementias are progressive, which means the symptoms will gradually get worse. Viewing dementia as a series of stages (e.g. mild, moderate and severe) can be a useful way to understand the progression of the condition, while appreciating that each individual will experience dementia in a different way and the different dementia subtypes will have different symptoms. For example Alzheimer's has a gradual onset while Vascular dementia usually has an abrupt start due to a stroke.

Symptoms common to most dementias are:

- a loss of short term memory
- disorientation to time, place and person, (perhaps don't know what time of day it is, or doesn't recognise a well-known person)
- poor concentration and being easily distracted
- a loss of language skills, like difficulties in finding the right word at times, including not being able to name people or specific items
- evidence of an inability to understand what is read or said to them
- evidence of not being able to think logically about issues or to carry out simple calculations
- evidence of visual and spatial difficulties which are not related to the health of the eyes

The severity of any symptoms, and when they occur during the disease, will be influenced by the type of dementia present. It should be noted that individuals can have more than one dementia. The term 'early onset' is used when an individual is diagnosed with a dementia before the age of 65 years.

If a person is concerned about their memory, thinking processes or ability to perform activities of daily living they should arrange an appointment at their GP surgery. Many surgeries now have a doctor and nurse who have a specific interest in working with individuals who have a dementia. The person will be asked to complete a basic cognitive assessment and receive a routine blood check. Following this consultation a referral might be made to the local memory clinic.

A Memory Clinic appointment will include appropriate history taking, a physical and basic neurological health check, mental health assessment and formal testing. Occasionally, an individual will be referred for a (CT, DAT or MRI) head scan. An opportunity to benefit from Cognitive Stimulation Therapy and medication may be offered.

An individual may perform within normal limits and therefore not receive a diagnosis while others receive a diagnosis of mild cognitive impairment (MCI). The latter is recognition that subtle cognitive changes have taken place but do not register severe enough to be recorded as a dementia.

Some individuals with a mild cognitive impairment will go on to develop a dementia and for this reason the individual, family, friends and the GP should monitor any changes. However, if an individual receives a diagnosis of Alzheimer's disease or Lewy Body disease, medication can be offered to help stabilise the dementia and maintain an individual's level of function. However, this treatment is not a cure as it does not alter the organic changes taking place in the brain.

Most individuals will have access to a memory clinic in their area and sometimes Community Mental Health Nurses (CMHN) will act as an extension to the memory service. CMHNs are highly skilled in working with individuals who have a dementia and also help and support carers including running carer support groups.

There has also been a move to provide memory advisors in this region, whose role is specifically to work with individuals with a dementia to help support and maintain normality for them by providing opportunities for social and mental stimulation, while the Admiral Nurse Service is geared to facilitating and assisting carers with their needs.

Memory Assessment and Research Centre (MARC) In addition to Memory Clinics, Dorset, Hampshire, Isle of Wight, Surrey and Sussex also have access to MARC at Moorgreen Hospital, which offers opportunities for individuals with dementias to participate in studies and drug trials. Direct contact can be made to this service (Tel 023 8047 5216).

Support Organisations In Hampshire, Southampton, Portsmouth and the Isle of Wight there are a number of different organisations, which provide services, specialising in advice and support for people with dementia.

Services available to individuals with a dementia and their carers include:

- Alzheimer's Society provides support and education
- Carers Together runs a variety of carers support groups, provides advocacy, support, training and awareness, benefits advice www.carerstogether.org.uk
- Dementia UK, who also supplies Admiral Nurses, specialising in caring for people with dementia www.dementiauk.org/information-support/

- There are also local MIND services, Age UK, Alzheimer's Cafes, Dementia Friends,

Further details can be found listed at the end of this booklet.

Dementia Road Map

The Dementia Road Map connects together high quality information about living well with dementia to support patients presenting with cognitive impairment and memory problems, their carers and families. This has been customised to include information about local services and resources. See <https://dementiaroadmap.info/> and select IOW or West Hants. Please note not all regions have chosen to develop this.

Keeping Healthy

Recommendations by clinicians to keep healthy are:

- Eat a healthy diet,
- Address high blood pressure and raised cholesterol levels if present.
- Exercise 2-3 times per week and
- Keep hydrated by drinking 1.5-2 litres per day.

Individuals also benefit from daily mental and social stimulation.

f. Dental Services

Everyone should be able to access good-quality NHS dental services. There is no need to register with a dentist. Simply find a practice that's convenient for you, whether it's near your home or work, and phone them to see if any appointments are available. Ask if you're not sure whether the practice provides NHS care.

If the dental practice you first contact is full or doesn't provide NHS care, this doesn't mean that no NHS dental care is available locally. NHS England is required to commission services to meet the needs of their local population, for both urgent and routine dental care.

There may be a high demand for NHS dentists in some areas and you may have to join a waiting list. You can do that by contacting NHS England. You'll be contacted as soon as an appointment is available.

Details of local dental services and particularly those with accessible facilities and those dentists willing to provide domiciliary dental services can be found by contacting the NHS Dental Helpline. Tel: 0300 311 2233 **Many people with Long-term Neurological Conditions qualify for NHS Community Dentists.**

Information on the dentists who are currently registering NHS patients can be obtained by contacting the NHS on 111 or to find a dentist, you can search on NHS Choices www.nhs.uk/NHSEngland/AboutNHSservices/dentists/Pages/find-an-NHS-dentist.aspx

g. Dietician Services

The quickest way to access dietician services is to ask your GP, consultant or specialist nurse for a referral to the service. A dietician can make recommendations and provide guidance on the best diet for your condition. Whether you consult a registered dietician or a registered nutritionist will depend on the kind of advice you want. You can find a registered dietician or a specialist dietician by using the contacts below:

- For general enquiries contact: NHS 111
- by contacting your local hospital or GP surgery
- by searching for a freelance dietician on the [Freelance Dieticians](http://www.freelancedieticians.com/) website, which is run in conjunction with the [British Dietetic Association \(BDA\)](http://www.bda.co.uk/) through the [Health and Care Professions Council \(HCPC\)](http://www.hcpc.org/)

h. Falls Prevention Services

Falls Prevention Services provide assessment of older people who have fallen, and/or are at risk of falls. They aim to find the causes and risk factors that contribute to falls risks and to ensure that risks are reduced as far as possible.

- If you're concerned that you may fall, or if you've fallen already, talk to your GP about falls prevention services in your area.
- Your GP may be able to refer you to a clinic, where you will have one-to-one time with a specialist falls prevention nurse to discuss your concerns. The falls prevention nurse may:
 - Talk to you about any existing health conditions or medicines that you are taking;
 - Ask you about your daily activities;
 - Test your balance;
 - Talk to you about foot care;
 - Ask you to provide a blood or urine sample;
 - The risk of you falling in the future will be assessed, and you will be given advice on how to improve your strength and balance and stay on your feet;
 - This might include a programme of exercises that you can do on your own, or you may be referred to an exercise class where you will be given exercises
 - If appropriate, you may be offered a scan of your bone density that will help to spot any early signs of osteoporosis.

Many falls can be prevented. By making some changes, you can lower your chances of falling. <http://www3.hants.gov.uk/adultsocialcare/adulthealthandwellbeing/preventingfalls.htm>

Falls Prevention Contacts:

Hampshire County Council. Email: wellbeing@hants.gov.uk

Southern Health

Elizabeth Kerridge-Weeks, Specialist Falls Prevention Lead. Tel: 07879 43233

elizabeth.kerridge-weeks@southernhealth.nhs.uk

Adrienne Phillips, Falls Prevention Coordinator Tel: 07584 616327

Email: adrienne.phillips@nhs.net or Adi.Phillips@southernhealth.nhs.uk

Hampshire Hospitals NHS Foundation Trust - Andover, Basingstoke and Winchester areas
Re-ablement Service (MP85), Therapy Services, Royal Hampshire County Hospital
Romsey Road, Winchester. SO22 6DG Tel: 01962 825630

i. Mental Health Service

People with neurological conditions can struggle with their emotions from time to time. It is natural to feel anxious or depressed – particularly when you are first diagnosed. As time goes on, these feelings may subside, but they can also reappear as your condition progresses. With some neurological conditions, psychiatric and / or cognitive problems can be the dominant symptoms which can begin insidiously and progress over the years. If any of these symptoms persist, contact your GP who should consider a referral to a specialist multi-disciplinary consultant led clinic.

If you are feeling stressed or anxious, it might help to speak to your GP about these concerns. They might be able to help by offering information and by signposting you to professionals who can help. The Primary Care Mental Health Team can assess and start supporting the problem. They are also known as IAPT (Improving Access to Psychological Therapies) and some run group relevant group treatments , on-line treatments including CBT (Cognitive Behaviour Therapy) and advise about self-help books. If problems are more serious or complex they will refer to the correct senior professional, informing your doctor. This may be to a psychiatrist, a specialist doctor in Secondary Care or nurse or psychologist.

j. Occupational Therapy

'Occupational therapists (OTs) are health and social care professionals who help people of all ages to carry out activities they need or want to do, but as a result of physical or mental illness, ageing, disability or being socially excluded, they are prevented from doing the activities they value. These could include the everyday necessities of daily living such as preparing a meal, getting dressed, going to school or work, or simply continuing with a favourite hobby.

OTs work with individuals to find alternative ways to do those activities, to help people live life their way. (The Royal College of Occupational Therapists, 2010)

RCOT Tel: 020 7357 6480 www.cot.org.uk

This can commonly include:

- helping people to manage the fatigue associated with their illness so that they can do all the everyday things that are important to them,
- supporting people to learn new ways to manage their anxiety,
- novel ways to manage their memory difficulties,
- more practical assistance such as finding new ways to carry out valued or essential activities, providing equipment to help where necessary and, in some cases, adapting the home environment and advising about more major modifications to your accommodation, and grants for this.

Hampshire Telephone number for OT direct: 0300 555 1378 or 1390

www3.hants.gov.uk/adult-services/adultservices-professionals/aboutas/structure/ot.htm

Isle of Wight Tel: 01983 534520 or 01983 552053 Integrated Occupational Therapy Service, South block, St Mary's Hospital, Newport, Isle of Wight, PO30 5TG

<http://www.iow.nhs.uk/our-services/community-services/occupational-therapy/1-occupational-therapy.htm>

Portsmouth Tel: 0300 3002012 Turner Centre, St James, Locksway Road, Portsmouth, Hants, PO4 8LD www.solent.nhs.uk/service-info.asp?id=43&utype=

Southampton Tel 023 8083 3003 Millbrook Healthcare Unit D, Centurion Business Park Bitterne Road West, Southampton SO18 1UB www.southampton.gov.uk/health-social-care/adults/help-at-home/Equipment-help-at-home.aspx

k. **Ophthalmology Service**

Health of the eyes is assessed by ophthalmologists who are specialist doctors with access to investigations looking at detail in all parts of the eyes. Some diseases of the eyes overlap with diseases of the brain. Ophthalmologists also work closely with community opticians who decide if glasses or contact lenses are needed.

l. **Orthotics**

The Orthotics Service (sometimes known as the Surgical Appliance Service) is responsible for the assessment and supply of equipment and appliances such as insoles, adapted shoes, leg splints and wrist supports. It can also be something more complicated such as a brace or calliper, depending on your individual needs. Access is via your GP. (Part of Podiatry)

m. **Palliative Care Services (Specialist and Hospices)**

Specialist Palliative Care

Specialist Palliative Care aims to help patients with life-threatening or degenerative illnesses, and their families to achieve the best possible quality of life. This might include:

- Helping you to live as actively as possible
- Taking account of your emotional, social and spiritual needs, as well as your physical ones;
- Supporting you and your family in coping with your illness and the choices you wish to make;
- Providing good relief from pain and other distressing symptoms

Your GP or consultant can refer you to the specialist palliative care services. It is often useful to make this referral early in your condition's progression so that you can meet members of the team and find out what they can offer.

The following link provides information and support for someone who is dying and for their carers, to enable them to achieve the best possible quality of life especially during the final stages of their illness. www3.hants.gov.uk/adult-services/carechoice/carers/end-of-life.htm#local

Hospices

Many Hospices now support people with a long-term neurological condition when they are approaching end of life. Contact the Hospice for more information. See list on page 17

Other Help

Carers Together	Tel: 01794 519495	www.carerstogether.org.uk
Dying Matters	Tel: 08000 21 44 66 (Freephone)	http://dyingmatters.org/
Macmillan	Tel: 0808 808 0000	www.macmillan.org.uk/Home.aspx
Marie Curie	Tel: 0800 716 146	www.mariecurie.org.uk/
Say it Once	Tel: 01794 519495	www.sayitonce.info

For information about hospice and palliative care providers in the UK

www.helpthehospices.org.uk/about-hospice-care/find-a-hospice/uk-hospice-and-palliative-care-services/

n. Pharmacy

Healthy Living Pharmacists and Community Pharmacists can do much to help you with your medicines and are always worth consulting if you have a query over your medicines.

www.nhs.uk/nhsengland/aboutnhservices/pharmacists/pages/pharmacistsandchemists.aspx

o. Physiotherapy

'Physiotherapy is a healthcare profession that works with people to identify and maximise their ability to move and function. Functional movement is a key part of what it means to be healthy. This means that physiotherapy plays a key role in enabling people to improve their health, wellbeing and quality of life.'⁵

They combine their knowledge, skills and approach to improve a broad range of physical problems associated with different 'systems' of the body. In particular they treat:

- neuromuscular (brain and nervous system)
- musculoskeletal (soft tissues, joints and bones)
- cardio-vascular and respiratory systems (heart and lungs and associated physiology).

You may wish to ask for a specialist neurological physiotherapist when you are referred as some only treat muscular skeletal problems.

Ask your GP for advice on the *local service contract* or ask for recommendations for local support groups as there are many different types of physiotherapy services and some might be more appropriate than others for you.

p. Podiatry

Podiatrists, who used to be called chiropodists, assess and treat foot care problems. These include corns, deformities due to arthritis and other diseases affecting nerve supply to the foot.

For information about podiatry or to find a podiatrist local to you, look on the NHS Choices website - www.nhs.uk/Service-Search/Podiatrists-and-chiropodists/Hampshire/Results/104/-1.288/51.067/343/9391?distance=25

q. Psychology

A range of support is available to people who have a life-threatening or degenerative illness.

As part of this, people may find it helpful to see a Clinical Psychologist who specialises in helping people and their families cope with the stresses and strains of such conditions.

Clinical Psychologists are usually accessed via your GP or mental health service, sometimes via a neuro-psychology, memory service or hospice. They can have very specific skills such as methods for working out which part of a person's brain is damaged and how to work around the deficit, in addition to helping a person, and their family coming to terms with a life-limiting condition and behaviour which can arise out of the damage to the brain.

r. Speech and Language Therapy

A speech and language therapist is a specialist health professional who assesses symptoms, plans treatment and treats people with communication and swallowing problems.

⁵ The Chartered Society of Physiotherapy, 2011

With **language problems** such as loss of speech (aphasia), the speech and language therapist will aim to assess and treat the underlying language problems. At the same time they will help the person minimise the difficulties these problems give them in everyday life.

With **speech problems**, the therapist's aim will usually be to make speech as understandable as possible. They will begin by making a detailed assessment of the person's speech and will then decide what can be done to improve things for them.

They can also advise re specialist exercises such as Lee Silverman technique for Parkinson's disease and help prepare people for artificial feeding via a "PEG" (Percutaneous Endoscopy Gastrostomy) when swallowing becomes difficult. Some areas run communication workshops or can arrange trying various forms of technology to assist, such as an iPad.

Communication Aids:

Hearing Loss www.nhs.uk/Conditions/Hearing-impairment/Pages/Introduction.aspx
www.abilitynet.org.uk/content/factsheets/pdfs/Communication%20Aids.pdf

Voice banking can be used for those with progressive weakness of facial muscles , such as Motor Neurone Disease , but also other diseases. Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so. This recording is then converted to create a personal synthetic voice.

When the person is no longer able to use their own voice, they can use the synthetic voice in speech-generating communication devices to generate an infinite number of words and sentences. The voice created will be synthetic and not be a perfect replica of the person's natural speech, but it will bear some resemblance.

Quote from a service user:

'All people are service users'.

*'Not just users of health and social care services,
but also a range of services in the community including:
police, ambulance, fire service, housing,
libraries, leisure services, shops, transport,
waste disposal, village / community halls,
and many others.....'*

6. Frequently asked questions and answers

Frequently asked questions - pages 31-32

a. Advice about my condition

Answers Page 33

- How can I learn to manage my condition myself?
- Who should I contact if I need support or advice?
- Where can I get information about my condition?
- Admission to hospital – what shall I bring?
- What tests may I expect?
- Sometimes I am confused about what all the terms mean?
- When should I contact the neurology service? I have concerns about changes in my physical ability – who can I ask?
- I am having difficulty coming to terms with the changes in my life due to my neurological condition. Who should I speak to?
- I seem to be waiting a long time for an appointment. Is there any way I can speed it up?
- It is difficult for me to get to hospital appointments, and the public transport is inaccessible or unavailable in my area. Am I eligible for transport to appointments? If so, how do I arrange it?
- Can someone assess my needs and provide help?
- I find coping with daily activities difficult
- I need equipment or adaptations for my home
- I have difficulty hearing and/or seeing

b. Carers Support

Answers Page 36

- Is there any way my spouse/family/carer can get training in moving/handling & first aid?
- How can my partner/parent/sibling get a break from caring for me?

c. Continuing Health Care and Personal Health Budgets

Answers Page 37

- How do I apply for Continuing Healthcare Funding?
- What do I do if I am turned down, and wish to appeal?
- Am I eligible for free prescriptions?
- What benefits may I be entitled to?

d. Home Adaptations and Equipment

Answers Page 39

- I am becoming increasingly disabled, and find it difficult to do simple things like answering the door, switching on the television and lights. Environmental Controls may help. How do I arrange for these to be fitted?
- What call systems are available for people in their own homes?
- What equipment should be provided through health and social services?
- Is there anywhere I can go to try out equipment (e.g. bath lifts, clos-o-mat) before I buy it?
- How do I apply for a Disabled Facilities Grant?
- Where can I get a stair lift, through floor lifts and automatic door openers?
- How do I get help with housework, gardening, simple DIY like putting up shelves, changing light bulbs, as well as larger home adaptations?

e. Planning Ahead and Advance Decisions

Answers Page 42

- How do I make a living will or record an Advance Decision to Refuse Treatment (ADRT)?
- Where would I go to make a Will? How much will it cost?
- How do I establish a Lasting Power of Attorney? How much will it cost?

f. Residential Care

Answers Page 43

- Where can I find information about local care and nursing homes?
- How do I apply for funding for Residential Care?
- Is there any other financial help available?

g. Social Care - services and funding e.g. Direct Payments, Support Plans Answers Page 44

- Is there anyone who can co-ordinate my care?
- I have heard people talk about Direct Payments. How do I find out more?
- Do I have any choice in home carers who come to the home?
- What elements of the care I need will be means-tested? Who do I contact to be means-tested, and how long will it take?
- What parts of my care will be free?
- What information, help, advice and advocacy is available if I pay for my own services?
- I have heard people talk about Direct Payments, Person Centre Planning, Personal Budgets, Personal Health Budgets and Support Planning. How do I find out more?

h. Travel, Transport and Driving Answers Page 47

- Information and advice about driving (e.g. can I continue to drive)?
- What happens when I contact the DVLA – will my licence be taken away?
- Am I eligible for the Motability Scheme?
- Where is the nearest Regional Driving Assessment Centre? (RDAC)
- How do I buy an adapted vehicle?
- Is there any financial help towards buying an adapted vehicle?
- How do I apply for a Blue Badge?
- Am I eligible for a Disabled Rail Card? How do I get one?
- Am I eligible for free or subsidised bus travel?
- Do local buses take wheelchairs and/or mobility scooters?
- Which taxi firms provide a service for wheelchair-dependent passengers?
- Are there any other transport schemes which may be able to help me?

i. Wheelchairs, Powered Wheelchairs and Mobility Scooters Answers Page 51

- How do I get a wheelchair? Will I have to pay for it?
- How can I choose the best type of mobility scooter?
- How do I get a powered wheelchair?
- Where can I get a hoist to put my wheelchair in the boot of the car?

j. Work, education, vocational, social schemes and support Answers Page 53

- Do I get any concessions for leisure activities, such as swimming, or evening classes?
- Are there any pools particularly suitable for people with disabilities?
- What facilities are in place to allow disabled people to pursue higher education opportunities?
- I am finding it difficult to use my computer and it is my lifeline. Is there any practical or financial support available to help me?
- Who can advise me about being able to continue working?
- Is there any financial support with adaptations, travel and support costs at work?
- Where do I go if I think I am being discriminated against in the workplace because of my disability?
- I am not able to continue to work in the same role – to whom can I speak about my options?
- I am now off sick from work due to my disability and cannot afford my rent. What can I do?
- Is there any financial help available for me to get to work?
- I want to go on holiday, but I need carers to help me with my personal care whilst I am away. Where can I find out about places which would be suitable?

Frequently asked questions with answers - pages 33-56

a. Advice about my condition

How can I learn to manage my condition myself?

Self-management is a way for people to take positive action in partnership with health and social care professionals caring for them, to reduce pain, improve the use of medication and enhance their overall quality of life.

To learn how to take an active role in the management of your condition discuss this with your GP, specialist nurse, or health or social care professional.

Do always **contact the relevant charity, self-help organisation** for your particular neurological condition as many run helpful sessions, regular group meetings, supply information leaflets and have a myriad of useful links and contacts.

For further information about organisations see section at back of this booklet.

Who should I contact if I need support or advice?

If you are under the care of a consultant, healthcare professional or specialist nurse then contact them in the first instance. If you do not have anyone assigned to you then speak to your GP.

Hampshire Neurological Alliance, HNA, offer advice and support as do each of the specialist organisations and charities listed at the end of the directory and Hampshire Carers Together. Many of these organisations run support groups, telephone contact, conferences and meetings, so you will find something that suits you.

Where can I get information about my condition?

For information about your condition your consultant, healthcare professional or specialist nurse should be contacted. If you are not under the care of any of the above then your GP would be able to give you advice about how to access information about your condition.

There may be a national charity which supports people living with the same condition that you have, and often they will be able to provide easy to understand information about the condition.

We would emphasise how useful it can be to have links with other people in similar situations to you. See page 57 for a list of national charities.

Admission to hospital – what shall I bring?

Consider preparing information, for the eventuality of a routine or emergency admission. Neurological conditions can be complex and relatively rare. Your condition may vary over the course of the illness and symptoms may mimic other conditions. This can be difficult for medical and nursing staff, who don't know you, or have limited experience of your condition.

The following information or documents may be helpful, especially if you find speech difficult or slow, or rely on others to help you:

1. Summary of your most important medical history, including approximate dates e.g. year of diagnosis
2. List of current medication, including doses and allergies - especially important for people with Parkinson's Disease and Myasthenia Gravis (support organisations will provide help on this)
3. Personal profile/contact details of next of kin or person with Lasting Powers of Attorney
4. Consider using "Say it Once" www.sayitonce.info/ Tel: 01794 519495
Email: contact@sayitonce.info or Hampshire Health Record <http://hantshealthrecord.nhs.uk> This is now called Care and Health Information Exchange CHIE.
5. Record of any Do Not Attempt Cardio Pulmonary Resuscitation (DNA CPR) document or Advance Decisions to Refuse Treatment (ADRT) or similar.

What tests may I expect?

As well as CT scans and MRI scans which may be done at your local hospital, there are other types of scans, tests of nerve conductivity and activity which may be carried out at the Wessex Neurological Centre in Southampton. Do ask if you don't understand what is involved. These specialist tests are performed by radiographers, who also carry out X-rays. Doctors called Radiologists interpret the results. A neuroradiology department also carries out PET scans and angiograms. The results may be complex to interpret; hence you may need a face-to-face discussion

with a neurologist to fully understand results. Sometimes a GP may be able to give you a result. Some tests may need a brief admission to hospital.

Sometimes I am confused about what all the terms mean?

Ask if you do not understand. Neurology is complex for everyone.

The following link is information from the Brain and Spine Foundation about various tests and conditions www.brainandspine.org.uk/neurological-topics-index

When should I contact the neurology service? I have concerns about changes in my physical ability – who can I ask?

If you have been referred by your GP to the neurology service and are awaiting your first appointment they will contact you with a clinic appointment. If there is a delay you should contact the secretary for general enquiries to find out when you will be seen. Also if you are awaiting a follow-up clinic appointment you may wish to find out when this is by contacting the secretary.

If you are under the care of a named consultant neurologist and you have a clinical or medical question for them you can call their secretary (referred to in the previous section). If you are under the care of a specialist nurse or professional allied to medicine, please inform them **immediately** of your change in health as this may result in a change of treatment.

If you have a **sudden** change in your condition such as paralysis it is important to contact your GP or emergency service on **999**.

I am having difficulty coming to terms with the changes in my life due to my neurological condition. Who should I speak to?

You may find it helpful to speak with your doctor or a health professional or perhaps get involved in a support group.

There's no definite time limit on the coping process. Everyone has a different process of coming to terms with and accepting a neurological condition. In fact, most people will find that emotions surface at all stages in the process. Even if treatments go well, it is natural to feel sad or worried from time to time; recognising and being aware of these emotions as they surface is all part of the coping process.

This is why HNA would encourage you, your family and carers, to make contact with your local / regional charity as there is much support to be gained from those who have also had some of these direct experiences. And do not forget, develop your own support network, trusted supportive professionals or friends who can be your advocate and support you through crises which will occur.

I seem to be waiting a long time for an appointment. Is there any way I can speed it up?

If you are waiting for an outpatient appointment with a hospital consultant, and it is your first appointment, you should speak to your GP in the first instance. With the help of your GP you may be able to choose an alternative hospital with a shorter waiting time.

If you have already been seen as an outpatient and are waiting for a follow-up appointment you may contact the secretary of the relevant consultant in the first instance if you think it is taking too long,.

If you have been waiting a long time for a Social Care Assessment contact them directly and explain the urgency of your situation.

Hampshire The contact is <http://www3.hants.gov.uk/contactus/as-contacts.htm>

Tel: 0300 555 1386 ☐☐ between 8.30am to 5pm Mon - Thurs and 8.30am to 4.30pm on Friday

Tel: 0300 555 1373 ☐☐ after 5pm until 8.30am Mon - Thurs, after 4.30pm Fri to 08.30am Mon and all day on Bank Holidays

Isle of Wight If you are new to the service and feel you may need an assessment or support please contact the First Response Team on 01983 814980.

<https://www.iwight.com/Council/OtherServices/Adults-First-Response-Team/Contact>

<https://www.iwight.com/Residents/Care-and-Support/Adults-Services/Adult-Social-Care-Services/Assessment>

If you already receive a service, please call 01983 823340. www.iwight.com/Residents/Care-and-Support/Adults-Services/

Portsmouth Contact the adult social care helpdesk in the first instance. Tel: 023 9268 0810
However, if you already have a link or keyworker in Portsmouth adult social care services, contact them first. www.portsmouth.gov.uk/ext/health-and-care/health-and-care.aspx

Southampton <https://www.southampton.gov.uk/health-social-care/adults/help-at-home/default.aspx>
Contact: adult.contact.team@southampton.gov.uk Tel: 023 8083 3003
Southampton City Council Civic Centre, Southampton, SO14 7LY

It is difficult for me to get to hospital appointments, and the public transport is inaccessible or unavailable in my area. Am I eligible for transport to appointments? If so, how do I arrange it?

Please see the section on Transport for community transport options. Patient Transport is a service provided for patients who require skilled staff to support them to and from treatment due to their medical or mobility condition.

Transport to Hospital

Several organisations in your area can provide transport to hospital appointments or visiting or both. These services are much in demand and it is important to use them correctly.

Patient Transport services <http://www.portsmouthccg.nhs.uk/patient-transport-service.htm>

If you cannot use public transport then try contacting one of the voluntary organisations or car schemes which can be found in Hampshire County Council's

<http://www3.hants.gov.uk/adultsocialcare/hospitalstays.htm>

or NHS Choices transport <http://www.nhs.uk/chq/Pages/1079.aspx?CategoryID=68>

Isle of Wight Voluntary Car Service OPTIO Tel: 01983 522226 N.B. This service is unable to take wheelchairs. www.communityactionisleofwight.org.uk/what-we-do/services/voluntary-car-service

Can someone assess my needs and provide help?

Everyone is entitled to an assessment of their needs to see if the County Council can help. Our main emphasis is on providing help that will keep people living independently for as long as possible.

Whether you have a long-term impairment, have just come out of hospital or are struggling as a result of age or illness adult services may be able to help.

There are several options available, see details in section 'g' below entitled Social Care Services.

I find coping with daily activities difficult

If you, or the person you are caring for, are not coping with daily activities such as personal care or find meal preparation difficult, please contact your local Adult Services Department. Trained advisors will discuss your situation. If it is identified that you require further support, you will be referred onto the appropriate care management team.

I need equipment or adaptations for my home

If you are finding difficulty managing in your current housing and feel that some equipment or adaptations will assist you, you may want to speak to an Occupational Therapist at Adult Services. (See also later section on Home Adaptations and Equipment)

I have difficulty hearing and/or seeing

If you have a hearing loss or sight loss The Sensory Loss teams can carry out an assessment to identify the help you may need. Sensory staff can also provide training to help you find solutions to the everyday problems that arise and give information about the equipment available. For more information please contact:

Hampshire Sensory Professional Advisors Team via Adult Services Tel: 0300 555 1386

Email: Sensory.PAT@hants.gov.uk Text phone: 0300 555 1390

<http://www3.hants.gov.uk/adultsocialcare/adultservices/adultserviceteams/sensorylossteam.htm>

Isle of Wight Tel: 01983 821000 Ext 8442 Thompson House Sandy Lane Newport IoW PO30 3NA

<https://www.iwight.com/Council/OtherServices/Sensory-Support-Team/Contact>

Portsmouth Tel: 023 9268 0810 or Text 079 5653 5228

<https://www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care---help-with-specific-conditions.aspx> Email: sensoryteam@portsmouthcc.gov.uk

Southampton Contact: adult.contact.team@southampton.gov.uk Tel: 023 8083 3003

Southampton City Council, Civic Centre, Southampton SO14 7LY

<http://sid.southampton.gov.uk/kb5/southampton/directory/service.page?id=WLOWfR2DQf4>

b. Carers Support

There are many sources of support for carers and some of them are listed here. Please remember - you do not need to live with a person to be their carer.

Carers Together - Hampshire, Portsmouth and Southampton

9 Love Lane, Romsey SO51 8DE Tel: 01794 519495 www.carerstogether.org.uk/

Hampshire <http://www3.hants.gov.uk/adultsocialcare/carers/supportforcarers.htm>

Isle of Wight - Carers Support IoW Tel: 01983 533173 www.carersiw.org.uk.

<https://www.iwight.com/Residents/Care-Support-and-Housing/Adults-Services/Carers-Adult/Who-is-a-Carer>

Isle Help, 7 High Street, Newport, Isle of Wight PO30 1UD. Tel: 03444 111 444 <https://islehelp.me/>.

Portsmouth Carers Centre 117 Orchard Rd, Southsea PO4 0AD Tel: 023 9275 6780

<http://portsmouthcarers.org/>

<https://www.portsmouth.gov.uk/ext/health-and-care/carers/portsmouth-carers-centre.aspx>

Carers Assessment

Contact your local Adult Services department to ask for a Carers Assessment – your partner or family carer is entitled to one by law. An assessment is the gateway to a range of support services.

Hampshire www3.hants.gov.uk/adult-services/care-services/carers.htm

<http://www3.hants.gov.uk/adultsocialcare/carers/carersassessment.htm>

<https://www.connecttosupporthampshire.org.uk/home>

Isle of Wight

www.iwight.com/Residents/Care-and-Support/Adults-Services/Carers-Adult/Who-is-a-Carer

www.iwight.com/Residents/Care-and-Support/Adults-Services/Carers-Adult/Carers-Assessment

Portsmouth <https://www.portsmouth.gov.uk/ext/health-and-care/carers/carers.aspx>

Southampton www.southampton.gov.uk/health-social-care/carers/carers-assess.aspx

www.southampton.gov.uk/health-social-care/carers/

General

www.nhs.uk/CarersDirect/yourself/help-for-you/Pages/helpandsupport.aspx

Is there any way my spouse/family carer can get training in moving & handling and first aid?

In short the answer is yes; contact any of the above plus here are some more specific links. Don't forget that moving and handling is easier for everyone with the correct equipment and adaptations around the house. Also see section 'd' on Home Adaptions and Equipment.

Hampshire Tel: 0300 555 1386

www3.hants.gov.uk/community-independence

Southampton

www.redcrossfirstaidtraining.co.uk/Where-we-train/South-east/Southampton.aspx

www.southampton.gov.uk/health-social-care/adults/help-at-home/Equipment-help-at-home.aspx

General

<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx>

<http://www.sja.org.uk/sja/training-courses/health-and-safety-courses/moving-and-handling/people.aspx>

<http://www.nhs.uk/CarersDirect/yourself/Pages/Yourownwellbeinghome.aspx>

<http://www.nhs.uk/CarersDirect/yourself/help-for-you/Pages/helpandsupport.aspx>

<http://www.redcrossfirstaidtraining.co.uk/Courses/First-aid-public-courses/First-aid-for-adult.aspx>

How can my partner/parent/sibling get a break from caring for me?

If your partner or family would like a break, respite care may be appropriate. It may be possible for you to stay in a residential or nursing home for a short period of time, giving them time at home or enabling them to take a holiday away. Some holiday options are also available around the country and abroad, dependant on your needs - for a holiday for you or a break away together, or as a family. They may also like regular short breaks for a few hours to pursue a hobby, take time off or perhaps they would just like a good night's sleep. There is a range of services that can provide trained people to look after you for just such purposes, during the day or night. Some are shown below:

Hampshire, Portsmouth and Southampton - Tel: 0300 555 1386

<http://www3.hants.gov.uk/respite> <http://www3.hants.gov.uk/adultsocialcare/carers.htm>

[http://documents.hants.gov.uk/adultservices/publications/ASpublicationsCarersTakeaBreakFeb2015.p](http://documents.hants.gov.uk/adultservices/publications/ASpublicationsCarersTakeaBreakFeb2015.pdf)

[df](http://documents.hants.gov.uk/adultservices/publications/SharedLivesRespiteFeb2015.pdf) <http://documents.hants.gov.uk/adultservices/publications/SharedLivesRespiteFeb2015.pdf>

Guide to Better Care and Support

Practical information on all aspects of independent living and support, with Part 2 of this booklet providing detailed listings of organisations providing home care services. On line this booklet comes in two parts - links to Part 1 and Part 2 are listed below:

<http://documents.hants.gov.uk/adultservices/publications/GuidetoBetterCareandSupport2016to2017PartOne.pdf>

<http://documents.hants.gov.uk/adultservices/publications/GuidetoBetterCareandSupport2016to2017PartTwo.pdf>

Guide to Residential Care

List of residential/nursing care homes; information/advice about choosing a care home. This booklet is listed on-line in four parts which can be found at this publications link below:

<http://www3.hants.gov.uk/adultsocialcare/adultservices/adults-publications.htm>

<http://www3.hants.gov.uk/adultsocialcare/housingoptions.htm>

Isle of Wight www.iwight.com/Residents/Care-and-Support/Adults-Services/

Good Neighbours Support Service www.goodneighbours.org.uk/

Carers Together - Hampshire and Southampton <http://782186386632763965.weebly.com/>
www.carerstogether.org.uk/

Vitalise www.vitalise.org.uk/centre-breaks/our-centres/netley-waterside-house-southampton/

The Rough Guide to Accessible Britain www.accessibleguide.co.uk/the-guide.html

c. Continuing Health Care and Personal Health Budgets

NHS Continuing Health Care and funded Nursing Care

NHS continuing healthcare is free care outside of hospital that is arranged and funded by the NHS. It is only available for people who need ongoing healthcare and meet the eligibility criteria described below. NHS continuing healthcare is sometimes called fully funded NHS care.

Where is care provided?

NHS continuing healthcare can be provided in any setting, including a care home, hospice or the home of the person you look after. If someone in a care home gets NHS continuing healthcare, it will cover care home fees, including the cost of accommodation, personal care and healthcare costs.

If NHS continuing healthcare is provided in the home of the person you look after, it will cover personal care and healthcare costs. It may also include support for carers – see [NHS Continuing healthcare FAQs](#) for more details.

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/NHSContinuingCare.aspx

NHS Continuing Health Care for Children

<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx>

Personal Health Budgets

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person (or their representative), their local NHS team and the local clinical commissioning group (CCG).

Personal health budgets enable people with long-term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive. They are initially available for people who are eligible for NHS Continuing Healthcare, who have had a 'right to have' a budget from October 2014. Clinical commissioning groups (CCGs) can also offer personal health budgets to others they feel may benefit from the additional flexibility and control. The NHS Mandate commits to a further roll out of personal health budgets to people who could benefit from April 2015.

At the centre of a personal health budget is the care and support plan. This plan helps people to identify their health and wellbeing goals, together with their local NHS team, and set out how the budget will be spent to enable them to reach their goals and keep healthy and safe. For more information about Personal Health Budgets:

www.nhs.uk/personalhealthbudgets
www.personalhealthbudgets.england.nhs.uk/

How do I apply for Continuing Healthcare Funding?

To apply for Continuing Healthcare funding locally you will require an assessment. The assessment of an individual's health needs is central to providing appropriate NHS health care including Continuing Healthcare services.

In many cases people with continuing healthcare needs will require additional specialist assessment. Specialist assessment is undertaken by appropriately qualified or experienced clinical staff and ensures that the individual receives the most appropriate health care. The decision as to whether an individual meets the eligibility criteria will be reached through the process of clinical assessment.

An assessment comprises many elements including:

- Assessing the individual patient's condition and health needs
- Establishing the health objectives for the patient
- Assessing the requirements for health services
- Identifying different health care treatment options
- Discussing health care treatment options with the patient and, if appropriate, with their carer
- Deciding the appropriate mode of delivery of services
- Agreeing the outline treatment plans including when it will be reviewed
- Agreeing a detailed treatment plan up to the first assessment
- Identifying the health professional's responsibility for reassessment

Specialist assessments are undertaken by clinicians who have additional recognised specific training and/or qualification, or expertise equivalent to a qualification, to that area of medical or nursing treatment. In the first instance you will normally be medically assessed by your GP or your consultant who may then refer you to the specialist service, usually for a multi-disciplinary assessment to determine what further help or treatment may be appropriate for you. For further information, please contact the local Continuing Healthcare team for your area:

www.nhs.uk/carersdirect/guide/practicalsupport/pages/nhscontinuingcare.aspx
www.nhs.uk/chq/Pages/eligibility-assessment-for-nhs-continuing-healthcare.aspx

What do I do if I am turned down, and wish to appeal?

Contact PALs - to find your nearest PALS office, look on the NHS Choices website:

<http://www.nhs.uk/chq/pages/1082.aspx?CategoryID=68>

You can also ask your GP surgery, hospital or phone [NHS 111](#) for details of your nearest PALS or contact your local Healthwatch. (See Appendix 1, Page 71)

If you are unhappy with the response to your complaint or appeal, you should be told that you can request an independent review from the Healthcare Commission. If you remain dissatisfied following a review or if a review is refused you can then approach the Health Service Ombudsman. The Ombudsman will normally expect complainants to have tried to resolve their concerns through the NHS complaints procedure before he or she considers taking a case on.

Am I eligible for free prescriptions?

A three monthly PPC (Prescription Prepayment Certificate) is available and saves you money if you need four or more items in three months. A 12 month discounted certificate is available and saves money if 15 or more items are needed within 12 months.

You can get free NHS prescriptions if, at the time the prescription is dispensed, you:

- are 60 or over
- are under 16
- are 16-18 and in full-time education
- are an NHS inpatient
- are pregnant or have had a baby in the previous 12 months and have a valid maternity exemption certificate (MatEx)
- hold a valid war pension exemption certificate and the prescription is for your accepted disability
- have myasthenia gravis
- have epilepsy requiring continuous anticonvulsive therapy
- have a specified medical condition and have a valid medical exemption certificate (MedEx)
- have a continuing physical disability that prevents you from going out without help from another person and have a valid (MedEx). The MedEx lasts for five years and then needs to be renewed. You may receive a reminder that your certificate needs to be renewed. If you don't receive a reminder, it is your responsibility to ensure that it is renewed.)

You are also entitled to free prescriptions if you or your partner (including civil partners) are named on, or are entitled to, an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or you receive either:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance, or
- Pension Credit - Guarantee Credit or Savings Credit

Telephone 0300 330 1341 for queries about medical exemption certificates.

www.nhs.uk/nhsengland/healthcosts/pages/prescriptioncosts.aspx

What benefits may I be entitled to?

There is a whole array of benefits which you may be entitled to and this depends on individual circumstances. Those people with a disability will usually claim one or more of the following:

- Disability Living Allowance (replaced in April 2013 by Personal Independence Payments, known as PIPs. www.gov.uk/pip)
- Severe Disablement Allowance (ceased 2000) www.gov.uk/severe-disablement-allowance
- Attendance Allowance www.gov.uk/attendance-allowance
- Carers Allowance www.gov.uk/carers-allowance
- Employment and Support Allowance www.gov.uk/employment-support-allowance
- Personal Independence Payments www.gov.uk/pip/overview

Rules are complex, some benefits are no longer available to new claimants and others are paid at different rates depending on the extent of your disability. Your entitlement to one benefit can also be affected by other benefits you may be claiming. It is always worth seeking independent advice and we would suggest you contact your local Citizens Advice Bureau in the first instance for comprehensive advice and assistance, or www.direct.gov.uk and www.gov.uk/browse/benefits

In addition to the above benefits there are a whole range of others designed to support people on low incomes including: Income Support, Employment Support Allowance, Income related benefits, Working Tax Credit, Job Seekers Allowance, Pension Credit, Housing Benefit, Child Tax Credit, Housing benefit, Disabled Persons Tax Credit Council Tax Benefit (reduction is based on mobility aids and needing more space to get around the house).

Again these are complex so seek advice. www.gov.uk/browse/benefits/jobseekers-allowance.

Disabled Facilities Grant

(Known as a DFG) is a local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the Council considers that changes are necessary to meet your needs, and that the work is reasonable and practical. Details of this are on page 40.

d. Home Adaptations and Equipment

I am becoming increasingly disabled, and find it difficult to do simple things like answering the door, switching on the television and lights. Environmental Controls may help. How do I arrange for these to be fitted?

Equipment and gadgets to help make life at home easier for you come in many shapes and sizes, some you might not have realised even existed.

It is useful to talk to other people, both peer support and professionals, about what they recommend, what they have got and how it helps, and if possible to see it and try it out before you commit to buying it. There are always new things coming onto the market, but do ask around before you invest in something which turns out not really to be what you will use.

Telecare and Telehealth are the terms used to describe services which use technology to help you live more independently at home. They include personal alarms and health-monitoring devices. Telecare and Telehealth services are especially helpful for people with long-term conditions, as they can give you and your relatives' peace of mind that you're safe in your own home and that your health is stable, without you having to make regular visits to your doctor's surgery. They can also help you live independently in your own home for longer, so you can avoid a hospital stay or put off moving into a residential care home.

Here are some information links about what is available.

General details www.nhs.uk/Planners/Yourhealth/Pages/Helpathome.aspx
www.nhs.uk/planners/yourhealth/pages/telecare.aspx

Hampshire

<http://www3.hants.gov.uk/adultsocialcare/managingathome/equipmentandadaptations.htm>
www3.hants.gov.uk/adult-services/carechoice/careathome/equipment/telecare.htm

Isle of Wight www.iwight.com/Council/OtherServices/Wightcare-Services/Telecare1

Portsmouth <http://portsmouthlocal.blogspot.co.uk/2011/02/portsmouth-city-councils-telecare.html>

Southampton

http://sid.southampton.gov.uk/kb5/southampton/directory/advice.page?id=KjAU6XA_yEI

What call systems are available for people in their own homes?

The following call systems provide 24 hour peace of mind. They consist of a small personal radio transmitter (pendant) that can be worn around the neck, clipped to clothing, or worn on a wrist strap. The pendant will trigger a base unit that will sit alongside your telephone. They are easy to use and keep clean. Simply press the red button on the alarm unit or the pendant and you will be connected to a control centre through your telephone line. Upon receipt of the call, the control room staff will talk to you over a loud speaker and identify the problem. They will decide what course of action can be taken, either by contacting your family, friend, or emergency service. Systems available include:

Hampshire www3.hants.gov.uk/adult-services/carechoice/careathome/equipment/telecare.htm

Isle of Wight www.iwight.com/Council/OtherServices/Wightcare-Services/Telecare1

Portsmouth www.portsmouth.gov.uk/ext/health-and-care/health/telecare.aspx

Southampton www.southampton.gov.uk/health-social-care/adults/careline-community-alarm.aspx

General information from Age UK

[www.ageuk.org.uk/products/mobility-and-independence-at-home/personal-alarms/?ito=GAG12604257607&itc=GAC52601660287&itkw="+telecare&itawnw=search&qclid=COHDisv4570CFdShtAod72UA9g](http://www.ageuk.org.uk/products/mobility-and-independence-at-home/personal-alarms/?ito=GAG12604257607&itc=GAC52601660287&itkw=)

What equipment should be provided through health and social services?

Hampshire

<http://www3.hants.gov.uk/adultsocialcare/managingathome/equipmentandadaptations.htm>

General <http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/equipment-aids-adaptations.aspx>

<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx>

Is there anywhere I can go to try out equipment (e.g. bath lifts, clos-o-mat) before I buy it?

The right equipment can make a big difference to your ability to live independently in your home. It's a good idea to get specialist advice and to always try out equipment before you buy it. Some Disabled Living Centres offer the chance to try out a wide range of equipment. They offer free, independent advice about what products are available, how much they cost and where to get them.

There are many pieces of equipment available that can help with everyday tasks so that a person can live as independently as possible, or to allow a member of the family or carer to assist with greater comfort or safety. They range from large items like hoists to help get out of bed, to small items to assist at meal times like angled cutlery or a non-slip placemat. There is also specialist equipment that can help if you have a sight or hearing loss.

Occupational Therapists can give advice and can make an assessment of need. Health staff can be accessed via doctors or special schools. Social care based Occupational Therapists can be accessed via OT Direct, 8:30AM -5:30PM on 0300 555 1384, or via email: OTDirect@hants.gov.uk

Local Disabled Living Centres:

Hampshire <http://asksara.dlf.org.uk/index.php?auth=hampshire&forceintro=true> You can borrow equipment for 2 weeks to see if it works for you with no obligation to purchase.

Isle of Wight <https://www.iwight.com/Residents/care-and-Support/Adults-Services/Home-Support-Services/Independent-Living-Centre1> Tel: 01983 241494

<http://www.peoplematteriw.org/independent-living-centre/4576855932>

Portsmouth Disability Forum www.p-d-f.org/?q=node/15

Southampton www.spectrumcil.co.uk/ Tel: 023 8033 0982 This centre in Southampton, previously known as SCIL, does not have equipment to try.

Assist UK leads a UK wide network of locally-situated Disabled Living Centres. Most centres include a permanent exhibition of products and equipment that provide people with opportunities to see and try products and equipment and get information and advice from professional staff about what might suit them best. www.assist-uk.org/centre-details

British Red Cross www.redcross.org.uk/What-we-do/Health-and-social-care/Independent-living

Simple equipment can be bought in high street shops and a list of local specialist stockists is available in the Yellow Pages under “disability” or “mobility”. Specialist disability equipment can be bought/sold or exchanged through the Disability Equipment Register.

Disabled Living Foundation <http://www.livingmadeeasy.org.uk/>

How do I apply for a Disabled Facilities Grant?

A Disabled Facilities Grant is a local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical. It can be used for adaptations to give you better freedom of movement into and around your home and/or to provide essential facilities within it.

If you are disabled, acceptable types of work include:

- widening doors and installing ramps
- providing or improving access to rooms and facilities – for example, by installing a stair lift or providing a downstairs bathroom
- improving or providing a heating system which is suitable for your needs
- adapting heating or lighting controls to make them easier to use
- improving access to and movement around the home to enable you to care for another person who lives in the property, such as a child

Hampshire www3.hants.gov.uk/redirect-district?LGSL=137&LGIL=8

Isle of Wight www.iwight.com/Residents/Care-and-Support/Housing/Housing-Renewals/Disabled-Facilities-Grants

www.iwight.com/Residents/Care-and-Support/Adults-Services/Independent-at-Home/Major-Adaptations

Portsmouth www.portsmouth.gov.uk/ext/health-and-care/socialcare/help-to-adapt-your-home.aspx

Southampton www.southampton.gov.uk/housing-council-tax/landlords-home-owners/homeowners/disabled-facilities-grant.aspx

General www.nhs.uk/Livewell/Disability/Pages/Independent.aspx

Other Adaptations and Equipment

Minor adaptations like grab rails or major adaptations like extensions or stair lifts can also make life easier. Home Improvement Agencies sometimes employ handyman schemes or contact your local District/City Council.

The Disabled Living Foundation helps older and disabled people find equipment to enable them to live independently in their own homes. www.dlf.org.uk www.dlf.org.uk/content/our-services

Their services include:

- a helpline service, which answers queries about equipment **0300 999 0004**
- an equipment demonstration centre, where you can try out equipment and get advice from occupational therapists and physiotherapists
- a range of online fact sheets to help you choose equipment, including stair lifts, hoists, scooters and household equipment

The foundation has also launched an online service to help choosing products around the bathroom, bedroom, stairs and telecare: the ‘Living made easy’ www.livingmadeeasy.org.uk website provides free, impartial information on all products available in the UK.

www.asksara.org.uk helps you find useful advice and products that make daily living easier.

Where can I get a stair lift, through floor lifts and automatic door openers?

There are many different types of stair lifts, from straight to curved, from new to reconditioned, from those to buy and those to rent; so talk to others and try them out before you commit yourself to one type or another. There are also through floor lifts and automatic door openers.

Hampshire

<http://www3.hants.gov.uk/adultsocialcare/managingathome/equipmentandadaptations.htm>

www.stairliftsuppliers.co.uk/stairlifts-hampshire.php

www.dolphinstairlifts.com/stairlifts.aspx <http://prismmedical.co.uk/product-category/stairlifts/>

Some stair lifts such as those made by Stannah are made in Andover, Hampshire. Tel: 0808 274 7152 www.stannahstairlifts.co.uk/

Isle of Wight www.islandmobility.co.uk/ Tel: 01983 530000
www.centralmobility.co.uk/stairlifts-isle-of-wight.cfm Tel: 0800 1 70 70 23

Portsmouth www.centralmobility.co.uk/stairlifts-portsmouth.cfm Tel: 0800 1 70 70 23

Southampton www.centralmobility.co.uk/stairlifts-southampton.cfm Tel: 0800 1 70 70 23

General www.ageuk.org.uk/ Tel: 0800 566 8435
www.nhs.uk/Planners/Yourhealth/Pages/Equipment.aspx

www.asksara.org.uk helps you find useful advice and products that make daily living easier.

How do I get help with housework, gardening, simple DIY like putting up shelves, changing light bulbs, as well as larger home adaptations?

Hampshire Details of Home and Garden maintenance

<http://www3.hants.gov.uk/adultsocialcare/managingathome/homegardenandpetcare.htm>

How to choose the right services?

Guide to Better Care and Support. Practical information on all aspects of independent living and support, with Part 2 of this booklet providing detailed listings of organisations providing home care services. On line this booklet comes in two parts - links to Part 1 and Part 2 are listed below:

<http://documents.hants.gov.uk/adultservices/publications/GuidetoBetterCareandSupport2016to2017PartOne.pdf>

<http://documents.hants.gov.uk/adultservices/publications/GuidetoBetterCareandSupport2016to2017PartTwo.pdf>

The Royal British Legion has a handyperson countywide for ex-service people and their families. They also offer some financial assistance.

www.britishlegion.org.uk/can-we-help/care-and-support/in-home-services/handy-van

www.britishlegion.org.uk/can-we-help/financial-assistance/grants-and-loans

For large adaptations, a Disabled Facilities Grant can be applied for (see page 40).

e. Planning Ahead and Advance Decisions

How do I make a living will or record an Advance Decision to Refuse Treatment (ADRT)?

It is best to seek advice from the health professional leading your care.

Some neurological support organisations have information about Advance Directive and Advance Decision to Refuse Treatment (ADRT) which can be sent to you or downloaded from the internet; for example, the MND Association produce a very good standard 'Living Will' form. If you would like a copy, <http://www.mndassociation.org/wp-content/uploads/2015/07/14a-advance-decision-to-refuse-treatment.pdf?1bcb49> please phone 01604 250505 or the MND Helpline 0808 802 6262 if thinking about these decisions is upsetting.

There is also a website: www.adrtnhs.co.uk with comprehensive information Tel: 01243 8663 9292.

Where would I go to make a Will? How much will it cost?

Most Solicitors provide a Will-writing service. It is well worth shopping around for the best price. Many will arrange a home visit in order to take your instructions in respect of your estate. Some people can get this free or at a reduced cost however, you must be aged over 75 and satisfy a means test requirement. Any solicitor offering advice under the Legal Advice and Assistance Scheme can give you more information about this. In addition to Solicitors there are some commercial Will-writing companies who advertise locally (See Yellow Pages). Costs will vary.

It is also possible to write your own Will. You should seek professional advice on how to do this and how to obtain the necessary forms. The Citizens Advice Bureau can give you more information about this. Information on this subject is also available from the various neurological charities.

Solicitors for the Elderly (SFE), is an independent, national organisation of lawyers, such as solicitors, barristers and legal executives. They provide specialist legal advice for older and vulnerable people, their families and carers.

The main areas of law members cover are:

- Making a Will, Powers of Attorney, Living Wills or Advance Directives
- Tax Planning, Asset Preservation, Trusts, Probate
- Paying for care, NHS continuing care funding
- Will disputes
- Court of protection and Elder abuse

Their site enables you to search for a solicitor, using a number of criteria. You can look at the profile of each solicitor to see if they specialise in the particular area of law you are interested in. Contact: www.solicitorsfortheelderly.com/ Email: admin@solicitorsfortheelderly.com admin@sfe.legal

How do I establish a Lasting Power of Attorney? How much will it cost?

The Public Guardian's Office gives full information on their helpful website: <https://www.gov.uk/power-of-attorney/overview>

A Lasting Power of Attorney is generally made to ensure that a loved one and/or relative can look after your affairs/best interests once you lack mental capacity to do this yourself. They are made in advance and can give you peace of mind that, should the worst happen, your chosen attorney will always be able to look after your best interests. If a person already lacks the necessary mental capacity they will be unable to create a valid Power of Attorney. However, concerned relatives can ask the Court of Protection to make decisions on behalf of someone who is having difficulties in making decisions themselves.

There are two basic types of LPA: one for your **finance and property** and another for your **health and welfare**. Different forms are needed for each LPA and you can download these from the above webpage. There is a fee for lodging a completed LPA with the Office of the Public Guardian. The forms are fairly straight forward to complete on line. However if you feel you need some help contact your local Citizens Advice Bureau, talk to a Solicitor for the Elderly or ask independent organisations such as Carers Together. Carers Together offers regular sessions to help with person centred planning, advance care plans and personal profiles. www.carerstogether.org.uk Tel: 01794 519495 Email: admin@carerstogether.org.uk You can also find useful documents on www.sayitonce.info

f. Residential Care

Where can I find information about local care and nursing homes?

There is a wide choice of residential care homes and nursing homes. The link below gives details of those in

Hampshire, Southampton, and Portsmouth:

<http://www3.hants.gov.uk/adultsocialcare/housingoptions.htm>

<http://www3.hants.gov.uk/adultsocialcare/adultservices/adults-publications.htm>

Isle of Wight

www.iwight.com/Residents/Care-and-Support/Adults-Services/Residential-Care/Care-Overview

General www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Carehomes.aspx

There are useful publications setting this information in print and on line as well as similar booklets explaining costs. In all cases you can contact your Local Authority to request a printed copy. Find retailers for Hampshire, Portsmouth and Southampton:

<http://www3.hants.gov.uk/adultsocialcare/adultservices/adults-publications.htm>

There are alternative choices to care homes such as Extra Care Housing and Shared Lives - here is a link to this information:

<http://www3.hants.gov.uk/adultsocialcare/housingoptions/otherhousing/extra-care.htm>

All Care Homes are inspected and regulated by the Care Quality Commission to ensure they meet national minimum standards of care. Inspection reports on care homes are available from CQC. Contact: The Care Quality Commission, St Nicholas Building, St Nicholas Street, Newcastle upon Tyne, NE1 1NB. www.cqc.org.uk Tel: 03000 616161

How do I apply for funding for Residential Care?

Here are Local Authority details about paying for care from Adult Services.

Hampshire www3.hants.gov.uk/adult-services/carechoice/payingforcare.htm

Isle of Wight <https://www.iwight.com/Residents/care-and-Support/Adults-Services/Adult-Social-Care-Finance/Residential-Services>

Portsmouth www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care.aspx

Southampton www.southampton.gov.uk/health-social-care/adults/residential-care-homes.aspx

Is there any other financial help available?

One of the best suggestions is to get in touch with your local neurological support group to enquire about this but there are some general suggestions as well.

Neurological Alliance www.neural.org.uk/living-with-a-neurological-condition/services

Family Fund www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/FamilyFund.aspx

Carers and Disability benefits information www.gov.uk/browse/benefits/disability

g. Social Care - services and funding e.g. Direct Payment, Support Plans

Is there anyone who can co-ordinate my care?

Obviously you and/ or your family can coordinate your own care if you wish. If you would appreciate advice and help with this, contact your local Adult Services at the Local Authority for this. Names and titles vary between organisations and agencies but you need to contact Adult Social Care services.

Hampshire <http://www3.hants.gov.uk/adultsocialcare/gettingstartedguide.htm#step-2>

Tel: 0300 555 1386

Isle of Wight www.iwight.com/Residents/Care-and-Support/Adults-Services/ Tel: 01983 823340

Portsmouth

www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care.aspx Tel: 023 9268 0810

Southampton www.southampton.gov.uk/health-social-care/adults/help-at-home/ Tel: 023 8083 3003

I have heard people talk about Direct Payments. How do I find out more?

Direct payments are cash payments given to service users in lieu of community care services that they have been assessed as needing. They are intended to give users greater choice in their care. The payment must be sufficient to enable the service user to purchase services to meet their eligible needs and must be spent on services that meet eligible needs.

You can opt to have **Direct Payments** rather than services (i.e. financial support rather than services in kind). All of the above contact links will explain this to you. When using Direct Payments you will coordinate your own care and support. Here is the link to this in general terms:

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Directpayments.aspx

Hampshire Tel: 0300 555 1386 www3.hants.gov.uk/direct-payments.htm

<http://www3.hants.gov.uk/direct-payments>

<http://documents.hants.gov.uk/adultservices/publications/DirectPayments-WhatyouneedtoknowMay2015.pdf>

Isle of Wight Tel: 01983 823340 <https://www.iwight.com/council/OtherServices/Personal-Budgets/Self-Directed-Support1>

Portsmouth Tel: 023 9268 0810 <https://www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care.aspx>

Southampton Tel: 023 8083 3003

<http://sid.southampton.gov.uk/kb5/southampton/directory/advice.page?id=i5cP8ggCSQ4>

If you need independent support with Direct Payments you can contact:

Carers Together www.carerstogether.org.uk Tel: 01794 519495 Email: admin@carerstogether.org.uk

Spectrum <http://directpaymentsouthampton.info/> Tel: 023 80202 931

Do I have any choice in home carers who come to the home?

Broadly the answer is 'Yes' you do, whether you coordinate your own care or others do. It's important that you feel at ease with the carers who support you. There is a wide range of private and public agencies, which provide home carers so you have many options to choose from and can mix public/state funded options with additional private purchased care. However, there may be a lack of choice in terms of the range, availability, specialisms and even costs, all of which may frustrate your choice. Here are details in addition to the links above:

Hampshire

<http://documents.hants.gov.uk/adultservices/publications/GuidetoBetterCareandSupport2016to2017PartTwo.pdf>

Isle of Wight <https://www.iwight.com/Residents/Care-Support-and-Housing/Adults-Services/Adult-Social-Care-Services/Care-at-Home>

Portsmouth www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care.aspx

Southampton www.southampton.gov.uk/health-social-care/adults/help-at-home/

General www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Homecare.aspx

What elements of the care I need will be means-tested? Who do I contact to be means-tested, and how long will it take?

Social care, such as help with washing, dressing, feeding and leisure activities, is available from Hampshire / other local authorities and in a variety of settings including your home. However, your needs will have to be assessed and part of this assessment process includes means-testing. Some people will be entitled to all their costs paid whilst others with savings may have to pay the full cost of the care they receive. Most will fall between these two points and will have to pay a contribution towards the costs of their care. Social care commonly means:

- Residential and nursing care
- Temporary or respite care
- Services you receive in your own home (home care) or at a Day Centre

Details about paying for care and eligibility in:

Hampshire Adult Services adult.services@hants.gov.uk Tel: 0300 555 1386 or in evenings and w/e's Out of Hours – 0300 5551373 www3.hants.gov.uk/adult-services/carechoice/payingforcare.htm

Isle of Wight Adult Services [Adults Services - Isle of Wight Council](http://www.iwight.com/Residents/Care-and-Support/Adults-Services/Adult-Social-Care-Finance/Overview5)
<https://www.iwight.com/Residents/Care-and-Support/Adults-Services/Adult-Social-Care-Finance/Overview5>

Portsmouth Adult Services www.portsmouth.gov.uk/ext/health-and-care/socialcare/adult-social-care.aspx

Southampton Adult Services Tel: 023 8083 3003
www.southampton.gov.uk/health-social-care/adults/help-at-home/

General www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Financialhelpwithsupport.aspx
www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Chargingforcareathome.aspx

What parts of my care will be free?

Some aspects of care may be free of charge, such as NHS Continuing Health Care. There may be grants and funding awards available from organisations/charities to assist you. Here is an overview:

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Financialhelpwithsupport.aspx

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/FamilyFund.aspx

Hampshire <http://www3.hants.gov.uk/adultsocialcare/moneyandbenefits/payingforcare.htm>

Isle of Wight www.iwight.com/Residents/Care-and-Support/Housing/Housing-Renewals/Disabled-Facilities-Grants

Portsmouth www.portsmouthccg.nhs.uk/nhs-continuing-healthcare.htm

www.portsmouth.gov.uk/ext/health-and-care/socialcare/help-to-adapt-your-home.aspx

Southampton www.southampton.gov.uk/housing-council-tax/landlords-home-owners/homeowners/disabled-facilities-grant.aspx

What information, help, advice and advocacy is available if I pay for my own services?

Adult Services Departments should give you advice and information.

You can also search on the internet for other organisations that may be able to support you.

I have heard people talk about Direct Payments, Person Centred Planning, Person Centred Coordinated Care, Personal Budgets, Personal Health Budgets, Personalisation and Support Planning. How do I find out more?

Direct payments See page 44

Person Centred Planning - Person Centred planning helps people to think about what they want now and in the future. It is a method of supporting people to plan their lives, work towards their own goals and get the right support when needed.

Person Centred Coordinated Care - Sometimes referred to as integrated care, person centred coordinated care means "I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me."

Personal Budgets - Personal budgets are an allocation of funding given to service users after a social care assessment. They should be sufficient to meet the individuals assessed needs. Service users can either take their personal budget as a direct payment; or can choose for themselves how their care needs are met and by whom, but leave councils with the responsibility to commission and pay for the services; or they can take a combination of the two.

Personal Health Budgets - See page 37

Personalisation - Personalisation is a social care approach described by the Department of Health as meaning that "every person, who receives support (whether provided by statutory services or self-funded), will have choice and control over the shape of that support in all care settings". Often associated with direct payments and personal budgets, personalisation also entails that services are tailored to the needs of every individual, rather than delivered in a one-size-fits-all way. It also encompasses the provision of improved information and advice on care and support for families; investment in preventive services to reduce or delay people's need for care; and the promotion of independence and self-reliance among individuals and communities.

Support Planning - Care and support planning is about you working with a care and support partner to think about:

- what is important to you
- things you can do to live well and stay well
- what care and support you might need from others

Support planning is for anyone who has health and care needs. These functions are often carried out by council social care staff and have been described as 'drawing up a support plan in partnership with the service user/carer, and providing information on, or sourcing services to implement, the support plan (brokerage)'. However, many people argue that they are better provided by external, independent, specialist organisations, including user-led organisations. A support plan is the means by which necessary information is presented to a local council in order for them to agree to release funds as a personal budget. It is a way of highlighting lifestyle choices of individuals, rooted firmly in what works for them as an individual. It demonstrates in practical terms how they will spend their budget to achieve their aims. In this way, the support plan reflects decisions made by the individual, supported by those whom they have chosen to assist them in this planning,

You are encouraged to prepare a support plan for yourself even if you are a self-funder and do not need Social Services support. If you need independent help with Support Planning contact one of the following

Carers Together www.carerstogether.org.uk Tel: 01794 519495

Spectrum www.spectrumcil.co.uk/independent-living/independent-living-services/direct-payments-in-southampton Tel: 023 8033 0982

In Control www.in-control.org.uk

National Voices has a guide that provides an introduction to care and support planning. It introduces the 4 stages of the approach and what should happen at each stage. It includes information about how care and support planning can help. www.nationalvoices.org.uk/what-care-and-support-planning

h. Travel, Transport and Driving

Information and advice about driving (e.g. can I continue to drive)?

You must tell the DVLA and your insurers if you have, or have ever had, a medical condition, neurological condition or an impairment that may affect your driving as this could make your insurance invalid. If you hold a current driving licence and have a 'notifiable' medical condition or disability, you must tell the DVLA right away. You should not wait until your licence is due for renewal. You must also tell the DVLA if your medical condition or disability has become worse since your licence was issued or if you develop a new medical condition or disability. If you are in doubt or unclear, speak to your GP.

'Notifiable' medical conditions and disabilities include: epilepsy, strokes and other neurological conditions, mental health problems, physical disabilities and visual impairments. The medical standards of fitness to drive are available to all medical practitioners. If your doctor, in accordance with these standards, has advised that you should not drive you may wish to surrender your licence.

If you have multiple sclerosis, motor neurone disease or Huntington's disease you must complete a questionnaire form CN1. If you have Parkinson's disease you must complete form PK1. Both these forms will allow the government medical adviser to contact your doctors and assess your capacity to drive. The forms are available from your doctor's surgery or online at:

www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRulesForDrivers/DG_10010623

What happens when I contact the DVLA – will my licence be taken away?

Once the medical adviser has all the information he/she needs, he/she will make a decision about your licence. You may be able to keep your licence or get a new one. You may be given a driving licence for a period of 1, 2, or 3 years if the medical adviser decides your 'medical fitness to drive' needs to be reviewed in the future. You may get a driving licence which states that special controls need to be fitted to the vehicles you drive so you can overcome the effects of a physical disability.

If the medical adviser's enquiries confirm that, as a result of your medical condition, you are not fit to drive, your licence may be withdrawn. If they have to take this course of action they will explain why they made the decision; tell you when you can reapply for your licence if possible; send you a notice explaining your right to appeal. You are required to inform your insurance company of your condition.

Am I eligible for the Motability Scheme?

The Motability Scheme can help you with leasing or buying a car if you are getting the higher rate of the mobility component of the Disability Living Allowance (DLA) or Personal Independence Payment (PIP). Even if you do not drive yourself, you can apply for a car as a passenger and propose two other people as your drivers.

If money is a problem when financing the car or adaptations, Motability may be able to provide a grant through their own charitable fund or the Specialised Vehicle Funds, which they administer for the government. Contact Motability: Tel: 0300 456 4566 or online at www.motabilitycarscheme.co.uk

Driving Ability Assessment

- If there is doubt whether you should continue to drive /resume driving
- If there is a neurological diagnosis / possible cognitive impairment
- If there has been a break from driving owing to illness / trauma / disability accident
- If you have a deteriorating condition

This type of assessment may involve a senior occupational therapist. This assessment may take up to 2½ hours. To contact the Driving Ability service for more information about having an assessment, contact your Regional Driving Assessment Centre. There are specialist companies who adapt cars, including those where a car can be driven from a wheelchair.

Where is the nearest Regional Driving Assessment Centre? (RDAC)

Regional Driving Assessment Centres give practical and independent advice and assessment to disabled drivers and passengers. The staff will assess your ability to drive, advise you about vehicles that might suit you and about any adaptations you may need. They are well informed on motoring

and disability issues. Talk to them about any mobility problems you have. At time of writing a Driving Assessment will cost £95 and a Transfer Assessment £59.

The nearest assessment centre can be found in Southampton at: **Wessex DriveAbility**, Leornain House, Kent Road, Portswood, Southampton SO17 2LJ Tel: 0300 456 4566 Email: enquires@wessexdriveability.org.uk Web: www.wessexdriveability.org.uk

The next nearest one is the **Oxford RDAC** Unit A, Anvil Court, Stanton Harcourt Road, Eynsham, Oxford OX29 4UD <http://www.rdac.co.uk/google-maps/>

Queen Elizabeth Foundation (QEF), in Surrey, has lots of useful mobility and neurological advice. QEF, Leatherhead Court, Woodlands Road, Leatherhead, Surrey KT22 0BN Tel: 01372 841100 Email: mobility@qef.org.uk Web: qef.org.uk, lists other services that they offer.

How do I buy an adapted vehicle?

Firstly, it is best to get advice from your nearest Regional Driving Assessment Centre (see above). If you are buying your vehicle under the Motability scheme, you may find the dealer nearest to you on their website: <http://motability.directenquiries.com/Motability/finddealer.aspx> and simply enter your postcode or alternatively Tel: 0300 456 4566.

Motability also produces a very useful booklet 'Choosing Your Car'. This is available for download from www.motabilitycarscheme.co.uk even if you are not buying your car through their scheme this booklet is full of very useful facts, tips and suggestions.

Is there any financial help towards buying an adapted vehicle?

The Motability Scheme can help you with leasing or buying a car if you're getting the higher rate of the mobility component of Disability Living Allowance (DLA). Motability offers a wide selection of vehicles for no more than the cost of your weekly mobility allowance, currently around £58 a week (higher rate). They have around 250 cars available with no advance payment. Other financial help may be available from local branches of national charitable organisations, available on their web sites or contact their helpdesks.

The Patient Advice and Liaison Service (PALS) may be able to do a search of charities and trusts that issue grants.

[http://www.nhs.uk/Service-Search/Patient advice and liaison services \(PALS\)/LocationSearch/363](http://www.nhs.uk/Service-Search/Patient%20advice%20and%20liaison%20services%20(PALS)/LocationSearch/363)

How do I apply for a Blue Badge?

The Blue Badge scheme is designed to give eligible drivers and passengers the ability to park close to the facilities and services they need to use, so as to improve their lifestyle, independence and freedom of choice. It may also give discounts on occasion e.g. Toll Road charges. All new badges issued are blue and are usable in all European Community countries.

Under current regulations governing the scheme, badges may be automatically issued to disabled people if they:

- Receive the higher rate of the mobility component of Disability Living Allowance (DLA) (help with getting about) or Personal Independence Payment (PIP)
- Are registered severely sight impaired
- Use cars supplied by a government department/receive a government grant towards their own vehicles
- Receive a War Pensioners Mobility Supplement

NB. If you have a terminal illness your application will be fast tracked

Other people may be issued a badge if:

- Their disability is permanent and substantial and makes them unable or virtually unable to walk. For example, applicants should generally be physically incapable of visiting shops, public buildings and other places, unless allowed to park close to their destination. Thus allowing the badge holder to take advantage of the access the badge has afforded.
- Their inability to walk or severe difficulty in walking is permanent and not intermittent or temporary. Things such as difficulty in carrying parcels are not taken into account.
- A person who regularly drives a motor vehicle but cannot operate, or has considerable difficulty operating, all or some types of parking meters or pay and display equipment.

A badge will not be issued under this rule to

- a person who will be travelling purely as a passenger
- a person who has a severe disability in both upper limbs
- a person with a temporary condition such as a broken leg

- a person with a psychological disorder, learning or behavioural difficulties unless the impairment causes very considerable, and not intermittent, difficulty in walking

If you feel that you qualify for a badge you will need to provide a photo. You will also need to sign the sticky label that with your photo will be put onto your badge and laminated. (Your photo should be placed face down on the dashboard, not on public display.) There is a small registration fee of between £10 and £17.50 depending on which Local Authority, as well as a small fee for replacement of lost badges. Please note, there are some minor differences between Local Authorities.

Hampshire	Tel: 0300 555 1376 www3.hants.gov.uk/bluebadge/bluebadge-apply.htm
Portsmouth	Tel: 023 9268 8304 https://www.portsmouth.gov.uk/ext/parking-travel-and-roads/parking/disabled-parking-and-blue-badges.aspx
Isle of Wight	Tel: 01983 823340 www.iwight.com/Residents/Care-and-Support/Adults-Services/Blue-Badges/Eligibility-Criteria1/
Southampton	Tel: 023 8083 3748 www.southampton.gov.uk/roads-parking/parking/blue-badge-parking/individual-blue-badge.aspx http://www.southampton.gov.uk/roads-parking/parking/blue-badge-parking/default.aspx
General	www.gov.uk/blue-badge-scheme-information-council

Am I eligible for a Disabled Rail Card? How do I get one?

A Disabled Rail Card will entitle you to 1/3 off travel for you and a companion. You are eligible for a disabled rail card if you receive:

- personal Independence Payment (PIP)
- Disability Living Allowance (DLA, low or high rate mobility or middle/high rate personal care)
- Severe Disablement Allowance
- War Pensioner's mobility supplement
- War or Service Disablement Pension (80% or higher)
- Are buying or leasing a vehicle through Motability

To apply for your railcard, which costs £20, Tel: 0345 605 0525 Email: disability@atoc.org

Further details on the National Rail website:

www.nationalrail.co.uk/stations_destinations/disabled_passengers.aspx

If you have difficulty with walking and need assistance at the railway station, it is possible to pre-book assistance with the relevant railway company www.gov.uk/transport-disabled.

Information about taking a wheelchair or mobility scooter contact:

www.nationalrail.co.uk/stations_destinations/44969.aspx

Assisted Travel on South West Trains - To book assistance or find out if stations are accessible contact South West Trains. If you need assistance to access their trains, it is recommended that you let them know 24 hrs before you travel. You can do this by contacting the Assisted Travel team on:

Tel: 0800 52 82 100 **Textphone:** 0800 69 20 792 or request assistance for your journey using their [online booking form](http://www.southwesttrains.co.uk/contact-us.aspx). <http://www.southwesttrains.co.uk/contact-us.aspx>

Am I eligible for free or subsidised bus travel?

Since April 2008 anyone in England who is 'eligible disabled' is entitled to free off-peak bus travel.

You are 'eligible disabled' if you:

- are blind or partially sighted
- are profoundly or severely deaf
- are without speech
- have a disability, or have suffered an injury, which has a substantial and long-term effect on your ability to walk
- do not have arms or have long-term loss of the use of both arms
- have a learning disability

You will need to apply to the local authority for your free pass and to renew an existing pass. They will tell you all you need to know about concessionary travel. You will need to prove that you are eligible, permanently live in the area and will need to provide them with a passport sized photo.

General information <https://www.gov.uk/apply-for-disabled-bus-pass>

Hampshire

For **bus passes only** the Hampshire County Council website www.hants.gov.uk/concessionary-travel http://www3.hants.gov.uk/passengertransport/concessionary-travel/guide_concessionary_travel.htm will give you direct links to the correct forms, or email [Concessionary Travel Team](mailto:Concessionary_Travel_Team) with any queries or Tel: 0300 555 1376 or Textphone: 0300 555 1390.

You can also find application forms in Bus stations, Adult and Children's Services local offices of Hampshire County Council, and District and Borough Council Offices.

Isle of Wight www.iwight.com/Council/OtherServices/Public-Transport/Fags

Portsmouth www.portsmouth.gov.uk/ext/parking-travel-and-roads/travel/help-with-travel.aspx

Southampton www.southampton.gov.uk/roads-parking/travel/smartcities-card/

General www.gov.uk/apply-for-disabled-bus-pass or <https://www.gov.uk/transport-disabled>

Do local buses take wheelchairs and/or mobility scooters?

Wheelchairs can be accommodated on most modern local buses, but this is not the case for mobility scooters. To check whether the buses on your local route are suitable for wheelchairs, telephone one of the telephone numbers above or try;

Traveline: 0871 200 2233 www.traveline.info for national and local accessible travel information.

Public transport information Tel: 0300 555 1376. Email: ptgenquiries@hants.gov.uk

Bus/Coach information: <http://www3.hants.gov.uk/passengertransport/useful-transport-links/linksbus.htm>

General Public transport information

<http://www3.hants.gov.uk/passengertransport/useful-transport-links.htm>

Blue Star Bus	0845 0727094	First Bus	0870 010 6022
Solent Blue Line	023 8061 8233	Stage Coach	0845 121 0180
Wheelers	02380 471800	Wilts and Dorset	01722 336855

For travel and accessibility info try: <https://www.euansguide.com/> or Tel: 0131 510 5106.

None of the regulations for buses or coaches deal with the carriage of scooters. This is because scooters are outdoor vehicles intended for use as an alternative to public transport for short trips. They are generally less manoeuvrable than wheelchairs and cannot be used as a seat on a vehicle because of their instability and difficulty in providing appropriate restraint systems for both the scooter and the user.

Shop Mobility Scooter Hire

These can be found at locations throughout the country. www.shopmobilityuk.org/

The National Federation of Shopmobility UK, known as NFSUK, can tell you nationwide locations. Tel: 01933 229644.

Hire is usually at a small fee. All schemes welcome a modest donation. They offer training on mobility scooters

Hampshire Shopmobility locations are:

Alton	Community Centre, Amery Street, Alton, Hampshire GU34 1HN Tel: 01420 85057
Andover	Bus Station, West St, Andover Tel 01264 352000
Basingstoke	Church Street, Basingstoke, Hampshire RG21 7QT Tel: 01256 476 066
Eastleigh	Unit 2, Swan Centre, Wells Place, Eastleigh SO50 9SG Tel: 023 8090 2402
Fareham	Osborn Road Car Park, Fareham, Hampshire, PO16 7DWTel: 01329 282929
Gosport	Bus Station South St Gosport Hampshire PO12 1ET Tel: 02392 502692
Isle of Wight	South Street, Newport (next to the bus station). Tel: 01983 718950
Portsmouth	Tel: 02392 816 973 www.portsmouthshopmobility.org/
Southampton	Tel 023 8063 1263 7 Castle Way, SO14 2BX
Winchester	Upper Parking Level, The Brooks Shopping Centre, Winchester Tel: 01962 842626

Which taxi firms provide a service for wheelchair-dependent passengers?

There are taxi firms who will cater for wheelchair users; the easiest way to find these are either via the local Councils who keep lists and contact details of these, yellow pages and the internet. Details of companies with wheelchair accessible vehicles in Hampshire and other taxi operators can be found in [Yellow Pages](#) or [Thomson local directories](#).

Taxis and private hire cars can be booked in advance to provide a door-to-door service and many drivers will help passengers get in and out of the vehicle or carry luggage and shopping. If you can transfer out of your wheelchair and your chair can be folded, most companies will carry your wheelchair in the boot free of charge. Further details <http://www3.hants.gov.uk/pttax>

Are there any other transport schemes which may be able to help me?

Community transport is a friendly, safe and affordable transport service, provided by local groups to help a range of people with transport problems. There are a number of schemes that operate locally. Some provide wheelchair accessible minibuses which provide door to door transport on request. Again, the best way to find out is via your Local Council.

Hampshire if you would like to hire a minibus, find out more about community transport in your area or even volunteer to drive, please contact your local community transport scheme:

www3.hants.gov.uk/passengertransport.htm

Isle of Wight www.iwight.com/Council/OtherServices/Public-Transport/Faqs

Portsmouth www.portsmouth.gov.uk/ext/parking-travel-and-roads/travel/help-with-travel.aspx

Southampton www.southampton.gov.uk/roads-parking/travel/smartcities-card/

General www.gov.uk/community-transport-services-shopmobility

i. Wheelchairs, Powered Wheelchairs and Mobility Scooters

Long-term services and equipment

Long-term services and equipment are provided by health services, via a referral from a GP, OT or physiotherapist. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-equipment-wheelchairs-scooters.aspx>

Short Term Services

British Red Cross Hampshire, Isle of Wight and Surrey

You can borrow equipment and mobility aids directly from the Red Cross on short-term loan basis. Red Cross have many centres around the Wessex region for these.

Not only wheelchairs but also walking frames, crutches, commodes and toilet frames come under the heading of Mobility Aids:

<http://www.redcross.org.uk/What-we-do/Health-and-social-care/Independent-living/Mobility-aids>

Wessex Regional Office 78-80 Walton Road, Woking, Surrey GU21 5DW Tel: 0345 0547 222
<http://www.redcross.org.uk/Where-we-work/In-the-UK/Southern-England/Hampshire-Isle-of-Wight-and-Surrey>

For first contact concerning mobility aids contact **Eastleigh Office** Unit 25, Parham Drive, Boyatt Wood Industrial Estate, Eastleigh, Hampshire SO50 4NU Main Tel: 02380 624 645

Isle of Wight Red Cross House □ Hunnycross Way □ Newport, PO30 5ZD Tel: 01983 522 718

Tips for choosing a wheelchair

<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-equipment-wheelchairs-scooters.aspx>

www.nhs.uk/carersdirect/guide/practicalsupport/pages/tips-for-choosing-a-wheelchair.aspx

There are three types of wheelchair:

- self-propelled – controlled by the user
- attendant-propelled – steered by someone else
- electric powered – class 2 for pavement use, and class 3 for pavement and road use

Before choosing a chair, think about whether it will be:

- for permanent or short-term use
- for indoor or outdoor use
- easy to get in and out of a car boot
- managed by the person using it, or with someone always there to help

There are advantages and disadvantages to each wheelchair, so the choice depends on what you need. For example, electric wheelchairs are good for outdoor use, but they can be heavy and awkward to transport.

Manual wheelchairs come as either standard or active-user type. A standard wheelchair can't be modified, but an active-user wheelchair can be adjusted and adapted to suit the needs of the user. Active-user wheelchairs are usually more expensive.

Staying Fit in a wheelchair www.nhs.uk/livewell/disability/pages/fitness-for-wheelchair-users.aspx

How do I get a wheelchair? Will I have to pay for it?

If you need a wheelchair for long-term use, ask your GP, District Nurse or other health professional to refer you to the NHS Wheelchair Prescription Service, which provides wheelchairs (with pressure cushions or special seating) to the residents of Hampshire, Southampton, Portsmouth, Isle of Wight with a permanent disability. Clients must meet eligibility criteria based on clinical need.

Assessments can be undertaken in your home if preferred.

www.nhs.uk/nhsengland/aboutnhservices/social-care-services/pages/nhs-wheelchair-services.aspx

Further details regarding provision of wheelchairs and a full list of NHS Wheelchair Services can be found at www.nhs.uk/Planners/Yourhealth/Pages/Equipment.aspx

Wheelchair Service by NHS in Hampshire and Isle of Wight

Millbrook Healthcare (operating as Hampshire Wheelchair Service)

Southampton, Portsmouth, Wincjester, Andover, New Fofest and surrounding areas

Telephone for queries: 0333 0038071

Telephone for repairs: 0333 0038072

Fax: 0333 0038073

Basingstoke Wheelchair Service

Basingstoke and surrounding areas

Telephone: 01256 376485

Fax: 01256 376481

Isle of Wight Wheelchair Service

Tel: 0330 124 4489

Fax: 0330 124 4490

General

www.ageuk.org.uk/

Don't forget it is possible to hire /rent a wheelchair for short term use; contact the British Red Cross for further details: www.redcross.org.uk/What-we-do/Health-and-social-care/Independent-living
www.asksara.org.uk helps you find useful advice and products that make daily living easier:

How can I choose the best type of mobility scooter?

If purchasing a scooter or buggy privately, it is essential to get as much independent advice as possible about the range of options.

A comprehensive advice fact sheet entitled 'Choosing a Buggy or Scooter' is available free from the Disabled Living Foundation, Disabled Living Foundation, 4th Floor, Jessica House, Red Lion Square, 191 Wandsworth High Street, London SW18 4LS www.dlf.org.uk Email: info@dlf.org.uk

Tel: 020 7289 6111 Helpline: 033 999 0004 Demonstration Centre 020 7432 8010

Assistance with funding may be possible from various charitable bodies. They can also be purchased through Motability by offsetting some or all of your Disability Living Allowance.

There are numerous Stockists of Mobility Scooters. Below are some links but there are plenty more:

Hampshire www3.hants.gov.uk/adultsocialcare/managingathome/equipmentandadaptations.htm

Isle of Wight www.islandmobility.co.uk/ Tel: 01983 530000

Portsmouth www.centralmobility.co.uk/stairlifts-portsmouth.cfm Tel: 0800 1 70 70 23

Southampton www.centralmobility.co.uk/stairlifts-southampton.cfm Tel: 0800 1 70 70 23

General www.ageuk.org.uk/

General www.nhs.uk/Planners/Yourhealth/Pages/Equipment.aspx

General www.nhs.uk/carersdirect/guide/transport/pages/motability.aspx

Motability www.motability.co.uk/scooters-and-powered-wheelchairs/

Shopmobility www.shopmobilityuk.org/ShopmobilityDirectory.asp

Ask Sara www.asksara.org.uk helps with useful advice and products for daily living.

How do I get a powered wheelchair?

If you are not eligible for an NHS wheelchair and would like advice on choosing a powered wheelchair and where to buy one, it is important that you shop around and try different models out. All the above links will give you relevant details.

Where can I get a hoist to put my wheelchair in the boot of the car?

If you are unable to lift your wheelchair into a car or if you have a heavy scooter or wheelchair, there are various types of equipment to help get it in the car.

- hoists which lift a manual or powered wheelchair into the boot of a vehicle
- rooftop hoists which winch a manual wheelchair up and on to the roof of a car
- racks which carry a wheelchair on the back of a car trailers and ramps.

Whatever type of equipment you want, talk to a Driving Assessment Centre about how the various alternatives available may suit you.

Southampton Wessex DriveAbility Leornain House, Kent Road, Portswood, Southampton SO17 2LJ Tel: 023 8055 4100 Email: enquires@wessexdriveability.org.uk www.wessexdriveability.org.uk

Oxford Regional Driving Assessment Centre, Anvil Court Unit A, Stanton Harcourt Road, Eynsham Oxford OX29 4UD www.rdac.co.uk/closest.php

Also seek advice from Motability www.motability.co.uk/scooters-and-powered-wheelchairs/

j. Work, education, vocational, social schemes and support

Do I get any concessions for leisure activities, such as swimming, or evening classes?

There are lots of opportunities for leisure activities and it is always worth asking at each of them if you are eligible to a concessionary rate. <https://www.moneyadvice.service.org.uk/en/articles/money-saving-tips-and-discounts-for-disabled-people>

General access information can be found at <http://www.disabledgo.com/> and at Euan's Guide <https://www.euansguide.com/>

Hampshire <http://www3.hants.gov.uk/adultsocialcare/thingstodo/socialactivities.htm>
<http://www.disabledgo.com/organisations/hampshire-county-council/main-2>

Hampshire and Isle of Wight <http://www3.hants.gov.uk/shiow/sporthampshire-getstarted/disability-sport.htm>

Isle of Wight <http://www.peoplematteriw.org/>

Portsmouth <http://www.pyramids.co.uk/access-scheme/> Tel: 023 9281

Southampton www.southampton.gov.uk/roads-parking/travel/smartcities-card/library-leisure-card.aspx

Are there any pools particularly suitable for people with disabilities?

In short the answer is 'Yes', there are many - please contact your local pools. For additional information about sporting activities:

Find a sport you can play

<http://parasport.org.uk/find-a-sport/?gclid=CKO2y-Gn770CFTMetAodW3UA7A>

General Disability Access www.disabledgo.com/

<http://parasport.org.uk/play-sport/sports-a-z/swimming?gclid=CMOqzpqg770CFYbMtAodg1AAwA>

The Rough Guide to Accessible Britain is available free for those with Blue Badge, Disabled Persons Railcard or Motability customers on www.accessibleguide.co.uk. The site is packed with useful information.

What facilities are in place to allow disabled people to pursue higher education opportunities?

There is considerable help, these websites give you a place to start finding out more:

<http://www.disabilityrightsuk.org/how-we-can-help/education-skills-and-employment>

www.gov.uk/browse/education

I am finding it difficult to use my computer and it is my lifeline. Is there any practical or financial support available to help me?

AbilityNet is a national charity helping disabled adults use computers and the internet by adapting and adjusting their technology. Their special expertise is ensuring that whatever your age, health condition, disability or situation you find exactly the right way to adapt or adjust your ICT to make it

easier to use, and they can offer remote support. They will send you a questionnaire to access your needs and they hold a bank of equipment which they can give out on long-term loan. The service is free to individuals and they have a tremendous success rate. AbilityNet Tel: 0800 269545. Email: enquiries@abilitynet.org.uk Web: www.abilitynet.org.uk/mcmw/

General advice including VAT relief

<http://www3.hants.gov.uk/adultsocialcare/disabilitysupport/trainingemployment.htm>

Who can advise me about being able to continue working?

Getting back to work and earning money may be at the forefront of many people's minds. There are ways and options to allow you to continue working, so don't be afraid to raise the issues with your employer, medical staff and others. Your GP and consultant can give you specific advice about your condition and how it will impact on your daily living. However, too often people are written off without thinking about what the person wants. Your local Jobcentre may be able to help. You will need to speak to a Disability Employment Advisor. You may also be able to gain assistance from Access to Work (see section on financial support available below).

You may consider that you need to seek independent advice about returning to work, talking with your employer or anything else worrying you about work or running your business. **Start Ability Services** www.startability.org.uk offer a national work advice service to people with long-term health conditions and organisations on removing the barriers to work. The Work Advice Line Service Tel: 01204 431638, Email: start.ability@ntlworld.com and by Skype: start.ability

Direct Gov

www.direct.gov.uk/en/disabledpeople/employmentsupport/workscchemesandprogrammes/dg_4000347 or <https://www.gov.uk/browse/disabilities/work>

Hampshire <http://www3.hants.gov.uk/adultsocialcare/disabilitysupport/trainingemployment.htm>

Is there any financial support with adaptations, travel and support costs at work?

If you need assistance with getting back to work, running your business and need support with doing tasks in your job, Access to Work may be able to help. **Access to Work** is a government scheme established to assist disabled people and those with a health condition.

You may be eligible for help if you are:

- in a paid job
- unemployed and about to start a job
- unemployed and about to start a Work Trial
- self-employed
- your disability or health condition stops you from being able to do parts of your job

Your disability or health condition may not have a big effect on what you do each day, but may have a long-term effect on how well you can do your job.

An Access to Work adviser can speak to you and your employer to reach a decision about the best support for you. In most cases, this can be done over the telephone, but a visit can be arranged if necessary. Sometimes specialist advice may be needed, which the Access to Work adviser will help to arrange. For example, your adviser may arrange for a specialist organisation to complete an assessment and recommend appropriate support. www.gov.uk/access-to-work

The amount of help which you may receive from Access to Work will vary depending on how long you have been employed, what support you need and whether you are self-employed.

Access to Work can pay up to 100 per cent of the approved costs of adaptations if you are:

- unemployed and starting a new job
- self-employed
- working for an employer and have been in the job for less than six weeks

Whatever your employment status, Access to Work will also pay up to 100 per cent of the approved costs of help with:

- support workers
- travel to work costs if you are unable to use public transport
- communicator support at interview

Access to Work pays a proportion of the costs of support if all of the following apply to you:

- you're working for an employer

- you've been in the job for six weeks or more
- you need special equipment or adaptations to premises

Access to Work will review your circumstances and the support you're receiving on a regular basis and at least once every 3 years.

Is there any financial help available for me to get to work?

Access to Work might pay towards the cost of getting to work if you cannot use public transport. You may be eligible for help if you are:

in a paid job; unemployed and about to start a job; unemployed and about to start a Work Trial; self-employed; your disability or health condition stops you from being able to do parts of your job

Your disability or health condition may not have a big effect on what you do each day, but may have a long-term effect on how well you can do your job. Ask the Disability Employment Adviser (DEA) at your local Job Centre about Access to Work.

Where do I go if I think I am being discriminated against in the workplace because of my disability?

If you think you are being discriminated against in the workplace you should seek expert advice.

The Equality Advisory Support Service (EASS) provides information and support on issues relating to **equality and human rights**, across England, Scotland and Wales. The website for the EASS is www.equalityadvisoryservice.com Helpline: 0808 800 0082) Monday - Friday 9am - 8pm and Saturday 10am - 2pm

The Advisory, Conciliation and Arbitration Service (ACAS) provides advice to both employees and employers regarding any employment issues. Their helpline is: 08457 474747 www.acas.org.uk

If you are a member of a Trade Union contact your local union representative as they can provide free advice and representation.

I am not able to continue to work in the same role – to whom can I speak about my options?

To find another job, your first point of contact should be the Disability Employment Advisor at your local jobcentre. You may also wish to look at the information in the section above "Who can advise me about continuing in work?" (Page 54) and contact <http://www.disabilityrightsuk.org/getting-advice>

I am now off sick from work due to my disability and cannot afford my rent. What can I do?

Seek advice from **Citizen's Advice Bureau** www.citizensadvice.org.uk/

I want to go on holiday, but I need carers to help me with my personal care whilst I am away. Where can I find out about places which would be suitable?

The national charitable organisations which represent the interests of people with neurological conditions such as the MS Society, Parkinson's UK and the MND Association all have helpline numbers and can provide advice and support regarding short breaks and holidays.

Each organisation has a wealth of experience and knowledge to advise people regarding practical issues with their own specific conditions. All keep details of places which are offering suitable holiday accommodation and personal care support. Telephone numbers for all the organisations can be found in the back section of the booklet. There is also a national charitable organisation which provides holiday information to anyone with extra needs:

Tourism for All c/o Vitalise Tel: 0845 124 9971 info@tourismforall.org.uk

Vitalise Formerly known as the 'Winged Fellowship', the organisation **Vitalise** can be contacted for comprehensive information on accessible holidays and carer support on www.vitalise.org.uk Tel: 0303 303 0145. This organisation has a holiday centre in Netley Waterside near Southampton <http://revitalise.org.uk/respice-holidays/our-centres/netley-waterside-house/>

The Rough Guide to Accessible Britain is available free for those with Blue Badge, Disabled Persons Railcard or Motability customers on www.accessibleguide.co.uk . The site is packed with useful information.

7. Useful Resources and Organisations

National Neurological Charities

Essential support & information from national sources. Discovering you are not alone can be so important. There is an extensive network of neurological charities offering support and information.

Neurological Condition	National Charity Details
Acoustic Neuroma Vestibular Schwannoma	British Acoustic Neuroma Association www.bana-uk.com Tel: <u>01246 550011</u>
Alzheimer's	Alzheimer's Society www.alzheimers.org.uk Tel: 0300 222 1122
Aphasia	Connect: www.ukconnect.org Tel: 020 7367 0840 Asphasia Now http://www.aphasianow.org/ Contact: online form Asphasia Alliance http://www.aphasiaalliance.org/
Ataxia (including Friedrich's Ataxia)	Ataxia UK https://www.ataxia.org.uk/ Tel: 020 7582 1444
Ataxia-Telangiectasia Louis-Bar Syndrome	Ataxia-Telangiectasia Society: www.atsociety.org.uk/ Tel: 01582 760 733
Autism	The National Autistic Society www.autism.org.uk/ Tel: 0808 800 4104
Bells Palsy	www.bellspalsy.org.uk/
Brain Aneurysm (unruptured)	see subarachnoid haemorrhage
Brain Haemorrhage	see subarachnoid haemorrhage
Brain Injury (Acquired)	UK Acquired Brain Injury Forum www.ukabif.org.uk Tel: 0845 608 0788 and 0345 6080788 Headway- see below
Brain Tumour	The Brain Tumour Charity www.thebraintumourcharity.org/about-us/contact/ Tel: 0808 800 0004
Cavernoma - Cerebral cavernous malformations Cavernous angioma	Cavernoma Alliance UK https://www.cavernoma.org.uk/ Tel: <u>01305 213876</u>
Cerebral Palsy	Scope www.scope.org.uk/home Tel: 0808 800 3333
Charcot Marie Tooth Disease	CMT UK www.cmt.org.uk/ Tel: 0800_6526316
Chronic Fatigue Syndrome:	See ME
Creutzfeldt-Jakob disease	CJD Support Network www.cjdsupport.net/ Tel: 01630 673973
Dementia	Dementia UK: www.dementiauk.org Tel: 020 7697 4160 Admiral Nurses Tel: 0800 888 6678 direct@dementiauk.org
Dysphasia	Speakability Since 2015 has become part of the Stroke Association www.speakability.org.uk Tel: 020 7566 1516
Dyspraxia	Dyspraxia Foundation Tel: 01462 455 016 or 454986 www.dyspraxiafoundation.org.uk/
Dystonia	The Dystonia Society www.dystonia.org.uk Tel: 020 7793 3650

Encephalitis	The Encephalitis Society: www.encephalitis.info Tel: 01653 692583
Epilepsy	Epilepsy Action www.epilepsy.org.uk Tel 0808 800 5050 Epilepsy Society www.epilepsysociety.org.uk Tel 01494 601 300/ 400
Essential tremor	National Tremor Foundation: www.tremor.org.uk Tel: 01708 386399
Fibromyalgia	Fibromyalgia Action UK www.fmauk.org.uk/ Tel: 0844 887 2444
Guillain Barré Syndrome	Guillain Barré Syndrome Support Group: www.gaincharity.org.uk/ Tel: 0800 374803
Headway	Headway www.headway.org.uk Tel: 0800 800 2244
Hemifacial Spasm	www.patient.co.uk/health/hemifacial-spasm-leaflet www.dystonia.org.uk Helpline: 020 7793 3650
Hemiparesis	HemiHelp www.hemihelp.org.uk Tel: 0345 123 2372
Hereditary Sensory-Motor Neuropathies	See Charcot Marie Tooth Disease
Huntington's Disease	Huntington's Disease Association www.hda.org.uk Tel: 0151 331 5444
Hydrocephalus	See Spina Bifida
Joubert Syndrome K	Joubert Syndrome UK www.jsuk.org/ Tel: 07530 254743
Ménière's Disease	Ménière's Society www.menieres.org.uk Tel: 01306 876883
Meningitis	Meningitis Trust: www.meningitisnow.org/ Tel 0808 80 10 388
Mental Health	www.mind.org.uk/ Tel: 0300 123 3393 www.mentalhealth.org.uk/ www.mentalhealthintheuk.co.uk/
Migraine	Migraine Trust: www.migrainetrust.org Tel: 020 7631 6970 Migraine Action: www.migraine.org.uk Tel: 08456 011033
Motor Neurone Disease	MNDA Association www.mndassociation.org/ Tel: 01604 250505
Multiple Sclerosis (MS)	MS Society www.mssociety.org.uk Tel: 0808 800 8000
Multiple System Atrophy	Multiple System Atrophy Trust: www.msatrust.org.uk Tel: 0333 323 4591
Muscular Dystrophy	Muscular Dystrophy UK www.muscular-dystrophy.org Tel: 020 0800 652 6352
Myalgic Encephalomyelitis Myalgic Encephalopathy ADEM (Acute Disseminated Encephalomyelitis)	ME Association: www.meassociation.org.uk Tel: 01280 818968
Myasthenia Gravis and other Myasthenia Conditions	Myaware (formerly Myasthenia Gravis Association): Tel: 01332 290219 Email: info@myaware.org Website: www.myaware.org

Narcolepsy	Narcolepsy UK www.narcolepsy.org.uk Tel: 0845 450 0394
Neurofibromatosis	The Neuro Foundation www.nfauk.org Tel: 020 8439 1234
Pain and Pain Management	Pain UK
Parkinson's Disease	Parkinson's UK: www.parkinsons.org.uk Tel: 0808 800 0303
Polio and Post-polio Syndrome	British Polio Fellowship www.britishpolio.org.uk/ Tel: 0800 043 1935
Progressive Supranuclear Palsy	The PSP Association www.pspeur.org Tel: 0300 0110 122
Raynaud's Syndrome	Scleroderma and Raynaud's UK https://www.sruk.co.uk/ Tel: 0800 311 2756
Rett Syndrome	Rett UK http://www.rettuk.org/ Tel: 01582 798911
Spina Bifida	Spina bifida hydrocephalus Association is now known as SHINE www.shinecharity.org.uk/ Tel: 01733 555988
Spinal Cord Injury	Aspire: www.aspire.org.uk Tel: 020 8954 5759 Spinal Injuries Association: www.spinal.co.uk Tel: 0800 980 0501 or 01908 604 191
Spinal Muscular Atrophy (SMA)	The SMA Trust www.smatrust.org Tel: 01789 801155
Spinal Tumour	Brain and Spine Foundation: www.brainandspine.org.uk Tel: 0808 808 1000
Stroke	The Stroke Association: www.stroke.org.uk Tel: 0303 3033 100
Subarachnoid Haemorrhage	Brain and Spine Foundation: Tel: 0808 808 1000 www.brainandspine.org.uk
TIA	See Stroke
Tourettes Syndrome	Tourettes Action: www.tourettes-action.org.uk Tel: 0300 777 8427
Transverse Myelitis	The Transverse Myelitis Society: www.my.elitis.org.uk
Tremor	National Tremor Foundation (NTF) http://www.tremor.org.uk/ Tel: 01708 386399
Trigeminal Neuralgia	Trigeminal Neuralgia Association UK http://www.tna.org.uk/index.php Tel: 01883 370214
Tuberous Sclerosis	Tuberous Sclerosis Association: www.tuberous-sclerosis.org
Wilson's Disease	Wilson's Disease Support Group UK www.wilsonsdisease.org.uk/

'The journey of a thousand miles begins with one step.'
Lao Tzu

Regional and Local Groups

Many neurological conditions are uncommon or rare. Not all are included here and may not have local contacts. Also check National Groups. If you see any gaps please let us know.

ALZHEIMERS SOCIETY - Central West Area

Area: Berkshire (Reading), Buckinghamshire (Milton Keynes), Hampshire (Portsmouth, Southampton), Channel Islands, Isle of Wight and Oxfordshire (Oxford).

Address: Alzheimer's Society, 118- 128 London Street, Reading, Berkshire RG1 4SJ
Telephone: 0118 959 6482 **Email:** ese@alzheimers.org.uk

Area: Basingstoke & Petersfield Office Alzheimer's Society Ground Floor Room 3
8 Chequers Road, Basingstoke, Hampshire RG21 7PU
Telephone: 01256 363 393 **Email:** basingstoke-district@alzheimers.org.uk

Area: Portsmouth & South East Hampshire, Alzheimer's Society, Rooms 02RF28 & 03RF32, John Pounds Centre, 23 Queen Street, Portsmouth, Hampshire PO1 3HN
Telephone: 02392 892 035 **Email:** portsmouth@alzheimers.org.uk

Area: Southampton & Eastleigh Office, Alzheimer's Society, 40 Chamberlayne Road, Eastleigh, Hampshire SO50 5JH
Telephone: 02380 610 159 **Email:** southampton@alzheimers.org.uk

APHASIA

Asphasia Now, but has no regional groups <http://www.aphasianow.org/> **Contact:** [online form](#)

Asphasia Alliance <http://www.aphasiaalliance.org/>

Connect: www.ukconnect.org **Regional Group:** Christchurch Helen Mann Tel: 020 7367 0864
Email: helenmann@ukconnect.org

ATAXIA UK

Hampshire Support Group 75 Keyhaven Road, Milford on Sea, Lymington, Hampshire SO41
Telephone Contact Jenny Rose Tel: 01590 645739 **Email:** aandbmorris@gmail.com

AUTISM Hampshire

Head Office 1634 Parkway, Solent Business Park, Whiteley, Fareham, Hampshire, PO15 7AH
Tel: 01489 880881 www.autismhampshire.org.uk/contact-us.html

Community Access - Information, Advice, Projects.

Community Access - Southampton, Suite 1c, Fairways House, Mount Pleasant Road, Southampton, Hampshire, SO14 0QB **Tel:** 02380 633951

Email: communityaccess@autismhampshire.org.uk

Community Access - Portsmouth, Frank Sorrell Centre, Prince Albert Road, Southsea, Hampshire, PO4 9HR **Tel:** 02392 814 723

For more information on our Community Access please click [here](#).

Services for Adults Residential Care, Support Packages.

Anglesey Lodge, Anglesey Road, Alverstoke, Gosport, Hampshire, PO12 2DX

Tel: 02392 524243 **Email:** adultservices@autismhampshire.org.uk

For more information on our Services for Adults please click [here](#).

Domiciliary Support Services Supported Living, Employment and Education Support...

1634 Parkway, Solent Business Park, Whiteley, Fareham, Hampshire, PO15 7AH

Tel: 01489 880881 Ext 5 **Email:** domcare@autismhampshire.org.uk

For more information on our Domiciliary Services please click [here](#).

BRAIN TUMOUR

Brain Tumour Charity UK www.thebraintumourcharity.org/

Support and Info Tel: 0808 800 0004 **Email:** support@thebraintumourcharity.org

Regional Group Hampshire and Surrounding Areas contact Penny Spurr, Brain Tumour Support Worker, Tel: 07711 597166 / 0845 450 1039 or by email at penny@braintumoursupport.co.uk

BRAIN AND SPINE

Brain & Spine Foundation, LG01, Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE Tel: 020 7793 5900 Email: info@brainandspine.org.uk
Helpline Tel 0808 808 1000 Email: helpline@brainandspine.org.uk

CEREBRAL PALSY

For more information regarding any services within Hampshire please contact us 01256 328329 or email romanhouse@scope.org.uk to discuss your needs further.

CHARCOT MARIE TOOTH

CMT United Kingdom, 3 Groveley Road, Christchurch BH23 3HB
Freephone: 0800 6526316 Tel: 01202 474203 info@cmtuk.org.uk Email: enquiries@cmt.org.uk
Hampshire Group Coordinator: Terry Dean 023 8055 9307 Email: terry@cmtuk.org.uk

CHRONIC FATIGUE See ME

CORTICO BASAL DEGENERATION (CBD)

Hampshire Contact Louise Roberts-West Tel: 07721 073 342
Email: jockandloubby@googlemail.com
National Helpline on 0300 0110 122 or helpline@pspassociation.org.uk

DYSPHASIA

Speakability (Action for Dysphasic Adults) In April 2015, Speakability (Action for Dysphasic Adults) became part of the Stroke Association.

240 City Road, London EC1V 2PR Tel: 020 7566 1516 **Information Service and Helpline:**
Tel: 080 8808 9572. Email: melanie.derbyshire@stroke.org.uk

In Hampshire there is a local group in Farnborough. Please contact London office for more details. If there is no Group where you live and you are interested in forming one, please contact Melanie Derbyshire on **020 7261 9572**.

DYSTONIA

Dystonia Society 2nd Floor, 89 Albert Embankment, Vauxhall, London SE1 7TP
Helpline: 020 7793 3650 Office: 020 7793 3651 Email: info@dystonia.org
Hampshire local group in Wickham, East Hants, run by volunteers.
Contact Peter Cole 0845 899 7120. Email: info@dystonia.org

ENCEPHALITIS

Tim Bond, Regional Representative Volunteer based in Hampshire area provides local support and information to people affected by Encephalitis, their families and friends. For more information or how to get in touch please visit website www.encephalitis.info contact 01653 692583 or email: support@encephalitis.info

EPILEPSY

Epilepsy Society Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ
Tel: 01494 601 300 Helpline: 01494 601 400 www.epilepsysociety.org.uk/

Epilepsy Action New Anstey House Gate Way Drive Yeadon, LEEDS LS19 7XY

Phone: 0113 210 8800

www.epilepsy.org.uk

HEADWAY

Headway National www.headway.org.uk

Network support coordinator Hayley Cook, tel:07826 855811

Headway Southampton 120 Commercial Road, Totton, Hampshire, SO40 3AD

Tel: 023 8086 2948 Web: <http://www.headway-southampton.org.uk>

Headway Basingstoke Headway House, Homefield Way, Basingstoke, Hampshire RG24 9SP

Service Manager Heather Jury Tel: 01256 314969 Email: hjury@headwaybasingstoke.org.uk
Headway Portsmouth and South East Headway Portsmouth & South-East Hants, Mountbatten Centre, Grandstand Suite Mountbatten Centre Twyford Avenue, Portsmouth PO2 9QA
Service Manager Deborah Robinson Tel: 023 9266 4972
Email: deborah@headwayportsmouth.co.uk Website: www.headwayportsmouth.co.uk
Headway Isle of Wight Tel: 01983 874651 Email: hiowsecretary@gmail.com

HEMIPLEGIA

Joanna Griffin, Home Visitor (SOUTHERN ENGLAND and Wales) - joanna@hemihelp.org.uk
http://www.hemihelp.org.uk/families/useful_contacts/local_groups/joining/
Tel: 0345 123 2372 / helpline@hemihelp.org.uk

HUNTINGTON'S DISEASE ASSOCIATION

Regional Care Advisor (Hants, Berks, IoW) <http://hda.org.uk/>
Eve Payler Tel: 023 8061 2218 Email: eve.payler@hda.org.uk
Hants and IoW Branch: <http://www.facebook.com/Huntingtons-Disease-Association-Hampshire-and-Isle-of-Wight-Branch-1258972890798592>

M.E. ASSOCIATION

Local support groups <http://www.friendswithme.org.uk/>
<http://www.meassociation.org.uk/information-and-support-line/find-a-local-support-group/>
Hampshire-wide including IoW Hampshire Friends with M.E., c/o The Community Centre, Brinton Lane, Hythe, Southampton SO45 6DU Tel: 0845 834 0325
Email: membership@friendswithme.org.uk

MENINGITIS

Sonja Butler, Community Support Officer, SOUTH AND SOUTH EAST ENGLAND
www.meningitisnow.org/how-we-help/local-support/south-and-south-east/
Call Sonja on 0845 340 2454 or Email: sonjab@meningitis-trust.org to arrange a home visit or to talk about how we can help you.
Meningitis Now - Head Office, Fern House, Bath Road, Stroud, Gloucestershire GL5 3TJ,
Tel: 01453 768000 Email: info@meningitisnow.org
Lucie Riches Community support officer, mostly covering the East of England, London and South-East. If you, or someone close to you, has been affected by meningitis, Lucie will be on hand to provide a listening ear, information and support. Tel: 0345 340 2453
Mobile 07587 554848 Email lucier@meningitisnow.org [Central and East Facebook page](#)

MOTOR NEURONE DISEASE

Motor Neurone Disease Association Tel: 01604 250505 www.mndassociation.org
Hants, Dorset, IoW, Channel Isles South Central
Regional Officer - Louise Rickenbach Email: louise.rickenbach@mndassociation.org
Tel: 03453 751831 or 0777 4268931 MND Connect 0808 8026262
Local support groups
Southampton / Winchester Contact Mrs_rocket@hotmail.com Tel 023 8089 1842
Basingstoke Contact: mndconnect@mndassociation.org Tel 0808 8026262
Portsmouth Contact: andrew.lane72@sky.com Tel 01489 790978
Regional Delivery Manager Hilary Fairfield, , 03453 751858
Regional Contacts for Hants and IoW
<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-portsmouth-and-south-east-hants-group/>
Regional Contacts for North Hants
<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-north-hampshire/>

MULTIPLE SCLEROSIS

Local Network Officer working for the MS Society in Hampshire & IOW :David Light – phone 02084380780, mobile 07717277498 email david.light@mssociety.org.uk

NHS MS coordinator in Southampton is sarah.gibbs2@uhs.nhs.uk

There are ten branches of the MS Society across Hampshire and the Isle of Wight - please go to the website for details www.mssociety.org.uk based in Andover, Alton & Petersfield, Basingstoke, Farnborough, Gosport & Fareham, Isle of Wight, Lyminster, Portsmouth, Southampton and Winchester

MULTIPLE SYSTEM ATROPHY

Support for you <http://www.msatrust.org.uk/support-for-you/> Tel: 0333 323 4591
Emma Rushton **Information and Services Manager**, Multiple System Atrophy Trust ☐
Direct line: 0203 621 1348 ☐ www.msatrust.org.uk, emma.rushton@msatrust.org.uk

Samantha Pavey Specialist Nurse Tel: 0203 371 0003 / samantha.pavey@msatrust.org.uk

Jill Lyons Specialist Nurse Tel: 01934 316 119 / jill.lyons@msatrust.org.uk

Dorset Support Group – Contact the MSA Trust office on 0333 323 4591 or support@msatrust.org.uk for more information.

Wiltshire Support Group - Contact the MSA Trust office on 0333 323 4591 or support@msatrust.org.uk for more information.

People in Hampshire may well attend our Surrey or West Sussex support groups too – Information on these can be found on our website www.msatrust.org.uk

MUSCULAR DYSTROPHY - No local group but on line discussion groups and support

www.muscular-dystrophy.org/how_we_help_you/care_and_support

<http://www.musculardystrophyuk.org/get-the-right-care-and-support/people-and-places-to-help-you/peer-support/>

South East Coast Muscle Group: Tel: 020 7803 4845 [Email: m.rees@musculardystrophyuk.org](mailto:m.rees@musculardystrophyuk.org)

Also at Muscular Dystrophy Campaign Tel 020 7803 4800 Email: info@muscular-dystrophy.org

MYASTHENIA GRAVIS AND OTHER MYASTHENIA CONDITIONS now MYAWARE

Myaware National (Derby) (formerly Myasthenia Gravis Association):

Myaware Hampshire Support Group Contact details from : 01332 290219,

Email: info@myaware.org Website: www.myaware.org/about-myaware

NHS Specialist Nurse (Hants, IOW, Dorset, Channel Islands)

Lisa Joyce Email: myasthenia@uhs.nhs.uk

NEUROFIBROMATOSIS

We employ a network of Specialist Advisors based within NHS Trusts around the UK. To see if there is one in your area, please call us on 020 8439 1234 or [click here](#) for information about them and their work. Rosemary Ashton – National Telephone Helpline – 07866 946 334

Carolyn Redman - South of England Local contact, based in Southampton and covering

Hampshire, Dorset, West Sussex, IoW Tel: 020 8439 1234

www.nfauk.org/about-us/specialist-advisors

PARKINSON'S DISEASE

Parkinson's UK has 3 local advisors covering Hampshire and Isle of Wight.

0808 800 0303 or www.parkinsons.org.uk for local contact details.

There are Local Branches in Alton, Andover, Basingstoke, Fareham, Hayling Island, Isle of Wight, New Forest, Portsmouth, Romsey, Southampton and Winchester there are also separate groups for younger sufferers.

SPINA BIFIDA

Southern Region Shine, Grove House, Suite 1a, London Road, Halstead, Kent TN14 7DS

Telephone: 01959 534618 E-mail: contact@shinecharity.org.uk

Naomi Marston Regional Development Manager Telephone: 01959 534618

Email: naomi.marston@shinecharity.org.uk Facebook: [Shine.Naomi.Marston](https://www.facebook.com/Shine.Naomi.Marston)

Shine South Web: www.shinesouthcharity.org

Lorraine Norman (Vice Chair) Tel: 07826 524673 Email : shinesouthcharity@gmail.com

Erica Maggs (Sec) Tel: 01329 317494 / 07858 686286 shinesouthcharity@gmail.com

SPINAL CORD INJURIES

Spinal injuries Association (SIA) South

Peer Support Officer for South Coast Steve Brookes Tel: 07535 590510

Email s.brookes@spinal.co.uk. General info Tel: 01908 604191,

Advice Line Tel: 0800 980 0501 OR [CHAT ONLINE](#)

Outreach Team www.spinal.co.uk/page/outreach-team

Websites by SIA members <https://www.spinal.co.uk/your-community/websites-by-sia-members/>

STROKE

Helpline 030 3303 3100

Stroke Association 02380 720420 HantsStrokeSupport@stroke.org.uk

Esme Mutter, Head of Stroke – South 02380 720426 esme.mutter@stroke.org.uk

Stroke Association Communication Support in Hampshire:

hantscommunicationsupport@stroke.org.uk

New Forest:	Yvonne Hobbs	07515 596867	yvonne.hobbs@stroke.org.uk
West Hants:	Graham Wake	07717 275773	graham.wake@stroke.org.uk
North East and North Central Hants:	Sam Malkin	07764 905151	sam.malkin@stroke.org.uk
Portsmouth and South East Hants:	Carly Davey	07717 275850	carly.davey@stroke.org.uk
Southampton and Central Hants:	Suzie Maidment	07717 275818	suzie.maidment@stroke.org.uk

Other Stroke Association services in Hampshire:

Stroke Recovery Service, Portsmouth

Debby Lewis	07505 269845	debby.lewis@stroke.org.uk
Venita Symmons	07712 326997	venita.symmons@stroke.org.uk

6 Month Review Service, Portsmouth

Mandy Souter	07515 6596920	mandy.souter@stroke.org.uk
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There are 25 Stroke Clubs and Voluntary led groups across Hampshire and the Isle of Wight.

To search for your nearest club or group: www.stroke.org.uk/support/search

For services on the Isle of Wight please see page 66

TOURETTES

Hampshire, IoW, Surrey, Sussex Email: emma@tourettes-action.org.uk

<http://www.tourettes-action.org.uk/8-find-support.html>

<http://www.tourettes-action.org.uk/10-ta-groups.html?75#regiondetails>

Isle of Wight Support Organisations

ACQUIRED BRAIN INJURY

Headway IoW Local branch Joy Cleightonhills 01983 874651 hiowsecretary@gmail.com
NHS Specialist nurse in Southampton is Miranda.Gardner@uhs.nhs.uk

ALZHEIMERS SOCIETY

Isle of Wight - covered by Portsmouth Office - Rooms 02RF28 & 03RF32, John Pounds Centre, 23 Queen Street, Portsmouth, Hampshire PO1 3HN
Tel: 02392 892 035 Email: portsmouth@alzheimers.org.uk

ALZHEIMER CAFÉ UK

IOW Branch - Health conditions covered - Dementia – all types
Contact: Maggie Bennett Tel: 01983 220200 Email: alzheimercafeiow@btconnect.com
www.alzheimercafeiow.org.uk Facebook – AlzheimerCafeIOW Twitter - @AzCafeIOW

ATAXIA IOW Support Group Alan Reed 01983 867946 Email: punkyal1970@gmail.com

AUTISM INCLUSION MATTERS (AIM) GROUP

Tel: 01983 523000 - ask to speak to the AIM coordinator. Email: aimisleofwight@gmail.com
AIM is an Isle of Wight group for adults (over 18) who have Autism or Aspergers, also known as an Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). It is not a group for parents, carers or professionals. AIM is a user led group. This means that with support, people with ASD will decide what happens in the group and help to run it. It aims to help people with ASD who may feel lonely, find it difficult to meet people or make friends. Group members choose where to meet and the range of activities to do. They support members to find people with shared interests and build friendships. There is advocacy support to listen to what adults with ASD have to say about life on the Isle of Wight, and to make changes.

BRAIN TUMOUR

Support groups meets last Tues of each month at Wessex cancer trust Support Centre, 19- 21 Lugley St, Newport PO30 5HD

CHARCOT MARIE TOOTH - see Neuromuscular Diseases

DIFFERENT STROKES, Isle of Wight

Contact: Sue Preater Tel: 01983 533236 Email: isleofwight@differentstrokes.co.uk
Exercise classes for younger stroke survivors held at Laidlaw Hospital, St Mary's Hospital, Newport. Classes are a great opportunity to meet and share experiences with other stroke survivors. Classes are designed to accommodate a wide range of abilities and medical conditions. You can join at any time and attend as many sessions as you like. You can bring a carer or partner with you. The group is run by stroke survivor volunteers. (Also see Stroke below)

EPILEPSY

David Piggott IoW Coordinator Tel: 01983 405825 Email: davepiggott65@outlook.com
Patients with Epilepsy and families are welcomed by the Headway group even without a brain injury causing their epilepsy.

FIBROMYALGIA

Self-help support group meets in Ryde. Contact: Karen Smith Tel: 0844 887 2346
Email: iwfmsg.fibromates@gmail.com www.isleofwightfibromyalgia.webs.com
Facebook Fibromates-Isle of Wight Fibromyalgia Support Group
Health conditions covered - Fibromyalgia, Chronic Fatigue Syndrome, ME

HEADWAY ISLE OF WIGHT

Isle of Wight - Small Branch run by unpaid volunteers
Riverside Centre The Quay, Newport PO30 2QR Tel: 01983 874651
Email: hiowsecretary@gmail.com

HUNTINGTONS

Regional Care Advisor (Hants, Berks, IOW) eve.payler@hda.org.uk Tel: 02380 612218
annette@scivier.uk

Several IOW families meet with Hampshire Branch.

Hants and IoW branch: <https://www.facebook.com/Huntingtons-Disease-Association-Hampshire-and-Isle-of-Wight-Branch-1258972890798592>

MOTOR NEURONE DISEASE

Motor Neurone Disease Association, Isle of Wight branch

Contact: Maureen Martinez / Ann Marchant Tel: 01983 615 701 or 07922 12 34 16

Email: mam_nfm@yahoo.co.uk

Info, support and guidance - regular meetings, help with funding specialist equipment, team of trained visitors. Regional Care Development Advisers train volunteers - see Regional and Local Groups

Regional Contacts for IoW

<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-isle-of-wight-branch/>

Claire Tuckett Volunteering Development Co-ordinator (VDC) Mob: 07831 349382

claire.tuckett@mndassociation.org

MULTIPLE SCLEROSIS

Website <http://www.wight-ms.org.uk>

Facebook <http://www.facebook.com/MS-Society-Isle-of-Wight-Branch-154416151364531/>

Support Lead Jenny Harrod isleofwightsupport@mssociety.org.uk Tel: 07976 629012 (text or voicemail only)

Secretary Livvy Kane isleofwight@mssociety.org.uk

Charity Shop Manager Helen Downer 01983 867500 mssocietyshanklin@gmail.com

Specialist Nurse Eileen Morley Tel: 01983 552094 /07917 558154 Elaine.Morey@iow.nhs.uk

MUSCULAR DYSTROPHY CAMPAIGN, Isle of Wight Branch

Contact: Mr Colin M Baker Tel: 01983 242961 Email: feathers455@hotmail.co.uk

www.muscular-dystrophy.org www.facebook.com/muscular dystrophycampaign

MYASTHENIA GRAVIS & OTHER MYASTHENIA CONDITIONS

Myaware Isle of Wight Support Group, (formerly Myasthenia Gravis Association, Isle of Wight)

contact Myaware, tel: 01332 290219, email: info@myaware.org, website: www.myaware.org

NHS Specialist nurse (Hants IOW, Dorset + Channel Islands)

Lisa Joyce: myasthenia@uhs.nhs.uk or Tel: 02381 205948

NEUROMUSCULAR DISEASES

This includes muscular dystrophy and many rare types such as Charcot Marie Tooth.

NHS Neuromuscular coordinator and Specialist Physiotherapist

Tel: 07798 667784 Email: Sunitha.narayan@uhs.nhs.uk

CMT- Hampshire Group Coordinator: Terry Dean Tel: 023 8055 9307 Email: terry@cmtuk.org.uk

PROGRESSIVE SUPRANUCLEAR PALSY

No local contacts, specific NHS service or 3rd sector group known to Neuro Network

SPINA BIFIDA

Isle of Wight Association for Spina Bifida and Hydrocephalus

Secretary: Ms Freya Conway Tel: 07535 004502 Email: littleowl2013@gmail.com

Chairman: Anne Axford Email: anneaxford@gmail.com

Contact through the website, by email or by telephone. Website: www.iwasbah.com

Facebook: <http://www.facebook.com/pages/Isle-of-Wight-Association-for-Spina-Bifida-and-Hydrocephalus/585664281508543>

STROKE Support Service Isle of Wight:

Stroke Recovery Service:

Mary Barton: 01983 898301 mary.barton@stroke.org.uk

Heidi Kurowska: 01983 898302 heidi.kurowska@stroke.org.uk

Stroke Recovery Service - Communication Support:

Tina Cutting: 01983 612729 tina.cutting@stroke.org.uk

Isle of Wight Stroke Club - Health conditions covered - Stroke - CVA, TIA

Contact: Tel: 01 983 869 100 Email: enquiries@wightfightingstroke.org

www.wightfightingstroke.org

www.facebook.com/home.php#!/groups/i.o.w.strokeclub/

(Also see Different Strokes above)

Additional Support for People with Neurological Conditions on IOW

AGE UK

01983 525282 www.ageukiw.org.uk

IAG, Lifeline project, Handyperson, small repairs - no charge for labour only materials, gardening service, Just About You - personal assistant service, nail cutting service, dementia services, falls prevention, digital inclusion, good neighbour scheme, active network of social groups.

CARERS IOW & QUAY CARERS

Health conditions covered - Unpaid Adult Carers of Adults. Contact: Elizabeth Martin Tel: 01983 533173 <http://carersiow.org.uk/>

JOHN CHEVERTON INFORMATION AND SUPPORT CENTRE

Earl Mountbatten Hospice, Halberry Lane, Newport, Isle of Wight PO30 2ER

<http://www.iwhospice.org/about-us.aspx> Email: infosupport@iwhospice.org

Tel: 01983 535320 or 01983 535319

The centre is open to anyone and everyone affected in anyway by any potentially life limiting illness (this includes relatives, friends, carers and health care professionals). It is open Monday to Friday 10am-4pm on a drop in basis and has been designed to offer contact, support, information, signposting, direction and help, advice and guidance café, listening, travel information, counselling services, benefits advice, employment & legal advice. Someone will always be available to listen to you and discuss your needs.

THE HEIGHTS LEISURE POOL

The Heights The Broadway Sandown Isle of Wight PO36 9ET Tel: 01983 405594

Open 7 Days a week - call first to confirm opening times. Have a hoist to assist swimmers who have additional needs.

INDEPENDENT LIVING CENTRE (ILC) - user led organisation

Downside Community and Learning Centre, Furlongs, Newport, IOW PO30 2AX

01983 241494 www.peoplematteriw.org www.riversidecentre.org.uk

Assessment of needs (self-referral or referred), OT on site - is able to assess more complex needs and advise appropriately. Includes a centre to demonstrate adaptations IOW based organisation supporting those with Long-term Neurological Conditions and Carers -

PARES (Personal Recruitment and Employment Service) helps to link suitable personal assistant to client. Client is in control of the interview process.

TAP (Team Around the Person) assessment - ensures everyone around the person e.g. carers, support workers, family & voluntary organisations work together to support you.

ISLE HELP HUB

Centre in Newport for contacting the following: Citizens Advice Bureau, People Matter, Footprint Trust, Age UK IOW, Law Society, Community Action Isle of Wight Tel: 01983 823898

<http://www.islefindit.org.uk> Advice Hub, 7 High Street, Newport, Isle of Wight, PO30 1SS

LOCAL AREA COORDINATORS

Active knowledgeable coordinators in different localities connecting vulnerable people to build their vision of a good life. <https://iwight.com/Residents/Care-Support-and-Housing/Community-Health-and-Wellbeing/Local-Area-Coordination/Introduction7/> or via IOW Council 01983 821000

SHOP MOBILITY

Tel: 01983 718950 Email: info@iowshopmobility.org.uk

Run by volunteers, it supplies a mobility scooter and wheelchair hire service so people can shop independently. It is located in Newport Town Centre, on the corner of South Street/Orchard Street, beside the Church Litten Car Park, near the library and bus station. Office Open Hours / Hire Times: Tue 10.00 – 3.30, Wed 10.30 – 2.30, Thu 10.30 – 2.30, Fri 10.00 – 3.30

WEST WIGHT SPORTS CENTRE

Moa Place, Freshwater, IOW PO40 9XH www.westwight.org.uk

provides exercise and Information

Special care swimming sessions on Wednesdays with hoist, warmer water and extra staff to support.

WIGHTCARE

Bugle House, 11a High Street, Newport PO30 1TP

01983 821105 wightcare@iow.gov.uk and www.iwight.com/wightcare

Round the clock reassurance, personal alarms, assisted technology and telecare work in partnership with Health and Social Care. Responders are trained in First Aid. Short term, long-term and holiday/respite installations

ISLE ACCESS

A one-stop location for visitors and Isle of Wight residents searching for information about access at places and venues around the Island. Our listings include recommendations on accommodation and links to the transport companies that serve the Isle of Wight. We also provide disability awareness training, customer advisory groups, advice on completing access statements and much more www.isleaccess.co.uk 07522 558 999

Adult Services Contacts

Hampshire, Isle of Wight, Portsmouth, Southampton & Neighbouring Local Authorities

Dorset County Council

- Social care information: [Community Care \(Adult Social Care\) Services](#)
- Dorset Adult Access Team: 01305 221016
- Bournemouth Care Direct: 01202 454979
- Poole Helpdesk: 01202 633902

Hampshire County Council

- Adult Social care <http://www3.hants.gov.uk/health>
- Adult Social Care: 0300 555 1386
- Out of hours / Emergency contact: 0300 555 1373
- Email: adult.services@hants.gov.uk

Isle of Wight Council

- Adult Social Care: 01983 823340
- Social care information: [Adult Social Care /](#)

Portsmouth City Council

- City Helpdesk: 023 9268 0810
- Out of hours / Emergency contact: 02392 822251
- Housing: [PCC Housing advice](#)
- Email: cityhelpdesk@portsmouthcc.gov.uk

Southampton City Council

- Adult Services: 023 8083 3003 from 8.30am- 5.00pm (Friday 4.30pm)
- Out of hours / Emergency contact: 023 8023 3344
- Website: www.southampton.gov.uk/health-social-care
- Housing: www.southampton.gov.uk/housing-council-tax

Surrey County Council

- Adult Services: 0300 200 1005. Alternatively use SMS: 07527 182861
- Out of Hours/ Emergency contact Tel: 01483 517898 or via text direct, 18001 01483 517898 Email: edt.ssd@surreycc.gov.uk
- Social care information: <http://www.surreycc.gov.uk/social-care-and-health>

West Berkshire Council

- Adult Services: 01635 503050
- Out of hours / Emergency contact: 01344 786543
- Social care information: <http://www.westberks.gov.uk/index.aspx?articleid=27090>

West Sussex County Council

- Adult Social: 01243 642121
- Social care information: <https://www.westsussex.gov.uk/social-care-and-health/how-to-get-social-care-help/adults/how-to-get-adult-social-care-help/>

Wiltshire County Council

- General Enquiries 0300 456 0111
- Out of hours / Emergency contact: 0300 456 0100
- Social care information: [Health and Social Care](#)
- customeradvisors@wiltshire.gov.uk

Wokingham Borough Council

- Adult Social Care (Optalis): 0118 974 6800
- Out of Hours / Social care emergencies: 01344 786 543
- Social care information: <http://www.wokingham.gov.uk/care-and-support-for-adults/>
- Email: wokinghamdirect@wokingham.gov.uk

Additional Support for People with Neurological Conditions and Carers

Carers Together

Phone: 01794 519495 admin@carerstgether.org.uk
<http://782186386632763965.weebly.com/> www.southamptoncarers.org.uk/

Elderly Advice Council and First Stop Care Advice

Tel: 0800 377 7070 www.housingcare.org/ www.firststopcareadvice.org.uk/

Hampshire Neurological Alliance

Tel: 07847 794937 contact@hampshireneural.org.uk www.hampshireneural.org.uk

Queen Elizabeth Foundation

QEF, Leatherhead Court, Woodlands Road, Leatherhead, Surrey KT22 0BN

Tel: 01372 841100

<http://qef.org.uk>, lists services that they offer.

British Red Cross

www.redcross.org.uk/ Tel: 0344 871 11 11

Macmillan

www.macmillan.org.uk/Home.aspx Tel: 0808 808 0000

Marie Curie

www.mariecurie.org.uk/ Tel: 0800 090 2309

Dying Matters

<http://dyingmatters.org/> Tel: Freephone 08000 21 44 66

There are many patient groups online where you can connect with others, who have similar neurological conditions.

These can be invaluable in terms of not feeling alone in what you are experiencing.

Patient.co.uk is one site where you can obtain health information and connect to others via the forums section. www.patient.co.uk/

Facebook also has a number of closed patient groups for different conditions. www.facebook.com/

Appendix 1 What to do if you have a complaint

What to do if you are having difficulty in accessing the health or social care services you think you need?

There are three different routes, at least, that you might choose to use:

1 Complaints

If you have a personal *COMPLAINT* about something, use the **Complaints System**.

Every organisation you deal with has its own complaints system. Just ask to be informed about their complaints system and ask to register your complaint formally

e.g. When visiting your spouse in hospital you find them in a state of neglect (perhaps soiled in faeces) and you need to act quickly on each matter of personal, confidential concern.

2 PALS (Patient Advice and Liaison Service)

If you need *ADVICE* and don't know where to start, try the Patient Advice and Liaison Service, aka PALS

e.g. You are trying to get your spouse home from hospital and do not know where to start nor how to arrange support, then ask PALS to help you negotiate the system.

PALS can also be contacted for confidential, impartial help, advice or support or for information about making a complaint on health-related matters and are a point of contact for patients, their families and carers.

PALS will:

- Act impartially when handling patient and family concerns, liaising with staff, managers and where appropriate, relevant organisations to negotiate immediate or prompt solution
- Listen to your concerns, suggestions or queries
- Provide information on NHS Services
- Advise and support patient, their families and carers
- Help sort out problems with you or on your behalf.

You can find officers from PALS in your local hospital or find your nearest PALS office on the NHS Choices website. NHS Choices on www.nhs.uk

On the **Isle of Wight** the PALS Team is now called the **Quality Team**.

It has Patient Experience Officers (PEO's) in the Complaints/PALS team who will be able to offer initial advice and support and guide you through the complaints process.

Direct Tel: 01983 534850 or 01983 534420 or via the hospital switchboard 01983 524081

Email: quality@iow.nhs.uk or PALS@iow.nhs.uk

3 Healthwatch

If you have an *ISSUE* you'd like to highlight, approach local Healthwatch; **e.g.** If you have already made several complaints, or you and several others have experienced problems - perhaps you have found parking at hospital tricky and have missed an Out Patients appointment and know of others who have been in the same situation

Healthwatch is the independent consumer champion created to gather and represent the views of the public. It exists in two distinct forms:

Healthwatch England - at national level. www.healthwatch-uk.org/

Local Healthwatch - the aim of local Healthwatch is to give citizens and communities a stronger voice to influence and challenge how health/social care services are provided within their locality.

You can contact the local Healthwatch in your area through the following:

Southampton

The Voluntary Action Centre, Kingsland Square, Southampton, SO14 1NW

Tel: 023 8021 6018 www.healthwatchesouthampton.co.uk/

Hampshire

Write (free) at: Freepost RTHH-KGST-ZRBC, Healthwatch Hampshire, Westgate Chambers, Staple Gardens, Winchester SO23 8SR

Tel: 01962 440 262 www.healthwatchhampshire.co.uk/content/about-healthwatch

Isle of Wight

Isle Help Advice Hub, 7 High Street, NEWPORT PO30 1SS

Tel: 01983 608608 www.healthwatchisleofwight.co.uk/

Portsmouth

Unit 3, St George's Business Centre, St George's Square, Portsmouth PO1 3EY

Tel: 023 9397 7079 <http://portsmouthhealthwatch.blogspot.co.uk/>

Appendix 2

Enhancing the quality of life for people living with long-term conditions



The House of Care

Dr Martin McShane – Director (Domain 2) Enhancing the quality of life for people with Long-term Conditions, NHS England, writes:

“The NHS has a lot to celebrate: it has contributed to people surviving conditions that in the last century would have been fatal and contributed to an increasing life expectancy. That success has however created a new context for the health and care system: the emergence of non-communicable diseases or long-term conditions (LTCs) as the dominant challenge to health and care systems. It is estimated that LTCs consume around 70% of health and care resource expenditure. Moreover the pattern of LTCs is changing. Although great strides have been made in tackling individual conditions, increasingly individuals have to cope with multiple conditions. Society has changed as well. People have different expectations and the revolution in digital technology means the traditional role of the professional with a patient needs to be transformed as well.

Our system, designed for the 20th century, has to change and adapt to meet the challenges of the future. By listening to the experiences and feedback from people coping with LTCs it is evident that the individual needs to become central to how care is designed and implemented. Personalised care, which understands and supports the individual, is vital. There is no magic bullet which will support the delivery of personalised care but there is evidence that thinking systematically about the essential components does.

We need to continue to use the best clinical and organisational evidence and practice which has emerged from the condition specific focus developed over recent decades. This is the roof of the House and is supported by two walls. The first of these walls supports professional collaboration. Long-term condition management is about collaboration between professional specialists and generalists. It is about team work which puts the individual requiring support central to the endeavours of professionals. The second wall is about the individual and their carers. We need to support the potential of both the individual and their network of support to self-care. Self-care is not abandoned care but recognises that in the management of LTCs the individual with the conditions is an expert in their own right.

The foundations for the House are commissioning enablers. Planning, securing and monitoring investment on behalf of the individual and population to secure the best possible outcomes.

The House of Care takes a whole system approach to LTC management. It makes the person central to care. It is about aligning levers, drivers, evidence and assets to enhance the quality of life for people with long-term conditions no matter what or how many conditions they have. To make the House of Care a reality we have developed resources including an interactive toolkit, an information dashboard and a diagnostic tool which will help professionals, organisations and communities to make the changes at a local & personal level. NHS England will continue to make changes at a national level that support implementation whilst understanding where the real change happens.”

Appendix 3 NHS 111

NHS 111 is a new service that has been introduced to make it easier for you to access local NHS healthcare services in England. You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is a fast and easy way to get the right help, whatever the time.

NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

When to use it

You should use the NHS 111 service if you urgently need medical help or advice but it's not a life-threatening situation.

Call 111 if:

- you need medical help fast but it's not a 999 emergency
- you think you may need to go to [A&E](#) or need another NHS urgent care service
- you don't know who to call or you don't have a GP to call
- you need health information or reassurance about what to do next

For less urgent health needs, contact [your GP](#) or [local pharmacist](#) in the usual way.

If a health professional has given you a specific phone number to call when you are concerned about your condition, continue to use that number.

For immediate, life-threatening emergencies, continue to call 999.

How does it work?

The NHS 111 service is staffed by a team of fully trained advisers, supported by experienced nurses and paramedics. They will ask you questions to assess your symptoms, then give you the healthcare advice you need or direct you straightaway to the local service that can help you best.

That could be A&E, an [out-of-hours](#) doctor, an [urgent care centre](#) or a [walk-in centre](#), a community nurse, an [emergency dentist](#) or a late-opening chemist.

Where possible, the NHS 111 team will book you an appointment or transfer you directly to the people you need to speak to.

If NHS 111 advisers think you need an [ambulance](#), they will immediately arrange for one to be sent to you.

Calls to 111 are recorded. All calls and the records created are maintained securely, and will only be shared with others directly involved with your care

NHS Choices - can be helpful in less urgent situations with information from the **National Health Service** on conditions, treatments, local services and healthy living. Contact on: www.nhs.uk



Appendix 4 Reports and documents of interest

One Chance to get it Right 26 06 14 - Improving people's experience of care in the last few days and hours of life - (Leadership Alliance for the Care of Dying People). Find on: <https://www.gov.uk/government/publications/improvements-to-care-in-the-last-days-and-hours-of-life>

Fuller Working Lives – A Framework for Action June 2014 DWP

This publication explains the benefits of working longer and how we intend to help people have fuller working lives.

www.gov.uk/government/publications/fuller-working-lives-a-framework-for-action

Supporting people to manage their health - An introduction to patient activation

www.kingsfund.org.uk/publications/supporting-people-manage-their-health

Care Act 2014

www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm

Care Act 2014 Fact Sheets

www.gov.uk/government/publications/care-act-2014-part-1-factsheets

Mental Capacity Act 2005: post-legislative scrutiny by the House of Lords

Document can be obtained on:

www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

White Paper: Valuing every voice, Respecting every right - Government Response to the Lords Committee Report on the Mental Capacity Act

Documents can be obtained on: <https://www.gov.uk/government/publications/mental-capacity-act-government-response-to-the-house-of-lords-select-committee-report>

This has particular relevance to the Lasting Power of Attorney Health and Welfare.

Under the MCA the doctor does not have the power to over-rule the decision of the LPA Attorney. It is also not the case that if two doctors agree on a course of action it supersedes the LPA.

Over the coming year the OPG will be working with DH and health professional bodies to increase awareness and understanding of the MCA and LPAs. The planned work follows the committee recommendation that the OPG address 'the poor levels of understanding of LPAs among professional groups; especially in the health and social care sector, paying specific attention to the status of Lasting Powers of Attorney in decision-making'

Later Life Newsletters from DWP are available - obtain from

www.gov.uk/government/collections/later-life-newsletters



NEUROLOGICAL INFORMATION BOOKLET

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