

Foreword

Welcome to the third 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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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 a doctor or health professional tells.

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)*