

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. Continence 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.

Continence 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 Continence 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/aboutnhsservices/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.....'*