LIVING WITH dementia
Support and services for people with dementia and their carers
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About this booklet

This booklet has been produced to provide people with a diagnosis of dementia, their families and carers, with information about helpful support and services on offer for them from a range of organisations across Dudley borough.

It is intended to be a complete guide to dementia services all in one place. Access to appropriate advice and support has a huge impact on families affected by dementia.

The booklet will prove useful to you at various points in your journey, both now and in the future. You can dip in and out of it as the need arises, so that you find services and support as and when you are in need of them.
What is dementia?

Dementia is a physical illness that causes problems with memory, mood, thinking, speaking and doing. A person with dementia is not mentally ill.

There are many types of dementia, with Alzheimer’s Disease being the most common. Vascular dementia is the second most common type and high blood pressure and heart problems can increase your risk of developing this.

For more detailed information on the condition visit www.nhs.uk/dementia or www.alzheimers.org.uk

Signs of dementia

Dementia often develops slowly and the early signs are not always obvious. Symptoms similar to dementia can be seen in other illnesses. It can sometimes be hard to tell dementia from the usual mild forgetfulness that is a normal part of the aging process.
The following signs could be early symptoms of dementia and a person should see their GP if they are worried about any changes in:

- Memory (specifically memory loss)
- General mental functioning
- The ability to carry out daily tasks
- Personality
- Behaviour

If you are worried about someone you should encourage them to see their GP. The sooner they see their GP the better, as spotting signs of dementia early means the right early treatment and support.
Risk factors

As dementia is so common many of us will have a relative living with the condition, but this does not mean we will develop it too.

Dementia is caused by diseases in the brain and in most cases our likelihood of developing it will depend on our age, lifestyle and the environment we live in, as well as the genes we have.

Prevention

It’s a good idea to keep healthy by:

- Not smoking
- Controlling high blood pressure
- Reducing your cholesterol level
- Controlling your blood glucose if you have diabetes
- Exercising regularly
- Having a healthy weight
- Eating a healthy, balanced diet
- Only drinking alcohol within the recommended limits
Getting a diagnosis

Getting a timely and accurate diagnosis of dementia is important.

**Why is a diagnosis important?**

Diagnosing dementia and its type is important. It will ensure that the person with dementia gets the correct support and treatment and they can then plan for the future.

If you have concerns about your own or someone else’s memory loss you should visit your (or their) GP.

Having listened to you describing the symptoms and taking into consideration your medical history, the GP will then carry out a series of tests (these can include blood tests, memory tests and brain scans). The tests will rule out other possible causes for the symptoms.

The GP will then refer you to a Dementia Specialist Nurse if they are not able to make a diagnosis. The nurse will then discuss with you if you are developing dementia and if so what sort of illness is causing the dementia. There are three main areas to the assessment. Each gives a different sort of information. A diagnosis is made by putting these together like a jigsaw puzzle. One on its own is not enough to diagnose dementia. It is important not to rush the assessment so that it is as accurate as possible. The Dementia Specialist Nurse will see you at your home or in the GP surgery.
Support for people with dementia

Once a person has had an official diagnosis of dementia there is a whole range of support services on offer to suit the individual’s own needs.

Dudley dementia gateways

There are two Dudley dementia gateways located in Halesowen and Brierley Hill. They work to support people diagnosed with dementia, their families and carers. They are made up of staff from Dudley Clinical Commissioning Group (CCG) and the council’s adult social care team.

The gateways offer access to a wide range of support for a person with dementia, their family and carer. Dementia Advisors and Dementia Specialist Nurses work out of the gateways.

Dementia Specialist Nurses are clinical staff and are part of Dudley and Walsall Mental Health Partnership NHS Trust. They work to empower people to live well following a diagnosis of dementia. The also support families and carers. They work very closely with Dementia Advisors and GPs.

Dementia Advisors aim to assist the person with dementia, their carer and family to find their way through the care and support options available to enable them to live well with dementia.
They will focus on the person’s wellbeing rather than their condition.

These Dementia Specialists will:

- Work in partnership together
- Provide information and advice and maintain contact for as long as required
- Help the person with dementia and their carers to find the right support at the right time
- Build a support plan and strategies to help
- Support with advanced care planning as required

Once contact is made with a person, this contact and support will be maintained as long as the person is living in the community.

Support offered by the gateways focuses around four key areas:

- Prevention
- Respite
- Long term
- End of life
Prevention

Gateway staff work hard to help people diagnosed with dementia maintain their independence and continue living a full life for as long as possible. Information, support, guidance and signposting to other helpful services is offered. The gateways also have close links with support groups and community groups.

If you find that nothing is needed at present, the staff will remain a point of contact for the future.

Respite

The gateways offers support sessions according to a person’s needs, along with a respite facility. Daytime sessions are offered for the person with dementia, either as pop-in emergency sessions or on a regular basis. These offer a break for family members and carers and can be arranged to suit their needs.
Long term

If the person with dementia has more complex needs, they can attend a gateway on a more regular basis. There will need to be a social care assessment of needs and there is a charge for regular sessions.

Support sessions are available seven days a week. A range of activities and useful therapies are on offer. These include craft sessions, exercise classes, memory games and puzzles, reminiscence therapy, life book sessions, music, dance and gardening. There are multisensory stimulation rooms with lights, relaxing music and pleasant fragrances. Light refreshments and a midday meal are available.
The gateways will also continue to offer ongoing information and support to people with dementia, their families and carers. As the condition progresses, more, or different types of support may be required. The Dementia Advisors will continue assessing people’s needs and adjust support accordingly.

**End of life**

The gateways work closely with palliative care services and can arrange support from these, as needed.

Overall the gateways are safe, supportive and welcoming places for all people whose lives are being affected by dementia.

**For more information on the dementia gateways call 01384 816039 (Monday to Friday 9am - 5pm)**

**or contact the dementia gateways on:**

**Brett Young gateway (Halesowen) Call 01384 13600**

**Crystal gateway (Brierley Hill) Call 01384 813315**

Visit [www.dudley.gov.uk/dementia](http://www.dudley.gov.uk/dementia)
**Admiral Nurses**

The Royal British Legion works with Dementia UK to provide Admiral Nurses - a service that supports the Armed Forces community (serving men and women and veterans) who have been diagnosed with dementia, their families and carers. The focus of the service is to maintain independence and improve quality of life, as well as to provide the practical advice needed.

The nurses provide individual support for family, carers and people with dementia, including psychological support to help people understand and deal with feelings and emotions. They help carers develop and improve skills in care giving.

Please note that Legion beneficiaries can be either the person with dementia or the carer.

You can contact this service yourself to ask for help and Dudley borough is covered by the service.

**Call 0808 802 8080 from 8am to 8pm, 7 days a week**

**Visit www.britishlegion.org.uk/get-support/living-independently/admiral-nurses**

Admiral Nursing Direct is also on offer. Here a seven day a week telephone service is available to anyone.

**Call 0800 888 6678 for support, advice and information.**
Alzheimers Society - Dementia Support Workers

Dementia Support Workers support people with dementia, their carers and wider family. They work with people for a period of time to help with current difficulties, such as practical support in reducing social isolation and building confidence to maintain independence and increase peoples control of their lives.

There is no charge for this service offered by the Alzheimers Society.

Call 0121 521 3028 to ask for help

An Alzheimers Society home support service is also on offer which provides personal care and social support to the person with dementia. There is a charge for this service.

Call 0121 521 3020 to find out more

Visit www.alzheimers.org.uk to find out more about the Alzheimers Society, including Dementia Connect – a comprehensive services directory for people affected by dementia.
Living well with dementia

It is possible for people to live well with dementia. As we have stated there are many services working to support people with dementia, their families and carers, throughout Dudley borough.

Below we list some practical hints and tips which can make life easier for the person with dementia and their carer.

Practical tips

Dementia is a progressive disease and no two people will experience it in the same way. Some practical tips which may be of use are described below, but bear in mind that not all of these will apply to each situation.

It’s often helpful to maintain routines and keep things the same for the person with dementia. If there are changes, introducing them as soon as possible can give the person time to get used to new ways of doing things. Some people find that too many changes at once can be confusing.

It can be helpful to break things down into smaller manageable steps; everything in daily life we do is a series of tasks that can be broken down. Simple written instructions can also be useful, and it can help to focus on just one thing at a time.
**Appointments**

- Keep a calendar or diary visible and marked up-to-date. Encourage the person with dementia to get into the habit of crossing the days off at night before they go to bed.

- Highlight events and write on appointments or events as you get them.

- Keep your calendar or diary in an obvious place on view e.g. in the kitchen or by the telephone.

- Have a daily newspaper delivered; this can help as a reminder of the date and day.

- “Orientation” clocks are available which show the time, day and date, and am or pm.

- White-boards can be a useful way to see the current day’s events.
Reminders

• Make a daily to-do list and keep it somewhere visible e.g. on the fridge

• Suggest keeping a shopping list in a prominent place which can be added to as things are needed, and make sure this is taken shopping

• Use an alarm clock or timer as a reminder of appointments, when something is cooking or when medication is due

• Sticky notes can be useful as a prompt on front and back doors as reminders to lock them or take keys out; they can also be used as reminders for putting the bins out on the right day etc.

• Simple mobile phones can be used for reminders or calendars as well as for easy contact when out

• Devices are available which can play a recorded reminder (e.g. a reminder to take keys whenever the back door is opened)

• Ask the pharmacist for medication to be provided in a pre-sorted box (sometimes called a “Dosette” box)

• Automatic pill dispensers are also available which will “beep” when it’s time for medication to be taken

• You could encourage visitors to write in a book/diary saying when they were there
**Keeping track of items**

- It’s a good idea to encourage the person with dementia to get into the habit of keeping things like keys, purse and money in the same place.

- If it helps, use labels around the home; label cupboards, doors and drawers or use picture labels.

- Keep useful telephone numbers next to the phone, eg: next of kin, police, neighbours. Some telephones have pictures next to the number for easy dialling.

- Item locator devices can help locate commonly mislaid items in the home such as keys, wallets, glasses case etc.

**Going out**

If you are concerned that the person with dementia may get lost when they go out by themselves, then “safer walking technologies” may help. These devices are able to locate someone who may be lost, or who is in need of assistance. Dudley Telecare Service can help with this technology - their details can be found in the Useful contacts section of this booklet.
Organisations across Dudley borough are working to create dementia friendly communities, so that when people with dementia are out and about, people recognise the condition and are sympathetic to their needs. Many organisations have signed up to the Dudley Dementia Alliance.

**To find out more about Dudley Dementia Alliance call 01543 285955, or email kat.horner@alzheimers.org.uk**

**Books on prescription**

You can find Reading Well Books on Prescription for people with dementia at your local library. These books provide information and advice, support to live well, advice for relatives and carers and personal stories. They are endorsed by health professionals and comprise of a full reading list.
Carers peace of mind emergency card

If you look after someone with dementia, whether you are a friend, neighbour or relative, the Carers peace of mind emergency card is a free service which has been designed with you in mind.

This card aims to gives you peace of mind that should something happen to you then the person you care for will be supported in your absence. The scheme is administered by Dudley Carers Network (run by Dudley Council) in partnership with Dudley Telecare Service.

To qualify for the card the person that is cared for needs to live in Dudley borough, the carer can however live anywhere. Your information is recorded on the Dudley Telecare Service database. You are sent a card and key fob with a unique code number and a 24/7 365 days a year emergency telephone number. If you, the carer, has an accident or an emergency, the card should be with you in your purse or wallet. The Carers Network will then get in touch with the contacts who you have nominated to tell them their support is needed.

Call Dudley Carers Network on 01384 818723 to find out more
Carers, look after yourself

If you are caring for a person with dementia, it’s so important both for you and the person you care for, that you look after your own health and keep as well as possible.

Give yourself a break.

Everyone needs time for themselves to sort out those little jobs, to go shopping, enjoy a hobby or just put your feet up. Saying you can’t be there all the time, all day, every day, is not saying you don’t care.

Letting someone else take over.

It can be difficult for both the carer and the person they look after to “hand over” to someone else.

Following that first, sometimes difficult time many carers come to realise that the person they care for also benefits from their being able to let go. New people to talk to, or new things to do, can be a pleasure. If you can relax while someone else takes over can this often make things easier for you both in the long run.

Joining with others.

Whether this is talking to a close friend, sharing experiences at a support group, or talking to a professional, most people find talking to others can be of huge benefit. It can make a big difference to talk to someone who understands what you are going through and for you to know that you are not alone.
Group support

It can be very useful to talk to others who are also in a similar situation. Sharing hints and tips on living well, coping and caring can be hugely reassuring.

There are a number of dementia cafes, as well as carers cafes across Dudley borough where you can meet people, have a chat, coffee and get involved in sociable activities, as well as listening to guest speakers talking about things like finances or coping mechanisms. These groups welcome both the person with dementia, family members and carers. It is also a great opportunity to meet new people and socialise with others who are sharing similar experiences.
**Alzheimer’s Society**

Dementia Cafés provide an opportunity for people living with dementia, their families and friends to meet to gain information and advice about how to live well with dementia and meet professionals in a relaxed and friendly atmosphere. Staff and volunteers are on hand to offer support. The Alzheimer’s Society holds dementia cafés at three locations each month:

Nine Locks Community centre, Brierley Hill DY5 2UE
(second Monday of each month)

Beacon Centre for the Blind, Sedgley WV4 6AZ
(third Friday of each month)

Broad Meadows, Russells Hall DY1 2LL
(last Wednesday of each month)

**For further details contact Alzheimer’s Society on 0121 521 3028**

**Me, Myself and I Group**
This social group is run by families and carers of people with dementia. It is intended for both people diagnosed with the condition, as well as their families and carers. The group meets each month and offers social activities, outings and trips, as well as regular talks by guest speakers. A warm and friendly group, newcomers are always welcome.

**Call 07717 700732 for further details**

**Queens Cross**

A carers cafe runs at the Queens Cross Centre, Wellington Road in Dudley on the third Thursday of each month from 10.30am until 1pm. Everyone is very welcome.

**Call 01384 818723 to find out more**
More support for carers

There is lots of additional support on offer for carers of people with dementia. Along with the dementia gateways, support, information and advice is on offer from:

**Dudley Carers Network**

The Care Act 2014 set out carers rights in law, giving them the same rights to support as the person they care for. The Act introduced a national eligibility criteria for carers, which local authorities must use when deciding if a carers’ needs meet the new rules and therefore have eligible needs for support.

In Dudley borough the council’s Dudley Carers Network offers support for carers, as well as a carers assessment to all carers. This is available upon request. If the council decides a carer is not eligible for care and support, they will still be able to find information and advice through the Dudley Carers Network.

A lot of support for carers is provided in the form of support for the cared for person. This can range from advice and equipment through to longer term support. People who meet the criteria for longer term support can now have a personal budget to give them more choice in how to arrange the care.

If you feel that the person you care for needs support now, or you need support to care, contact the Network to ask for a carers assessment. There is no charge for this and lots of help on offer.
The Network also provides expert and impartial signposting, advice, benefits advice and information to carers by phone or email. They also run the Carers peace of mind emergency card. Regular newsletters keep carers up to date with changes, advice and local offers.

**Contact Dudley Carers Network on 01384 818723**

**Carers Assessments**

A carers’ assessment is an opportunity for you to discuss with the council your needs and feelings as a carer and what support or services you need to help you continue caring.

A carers’ assessment will look at:

- Your needs for support
- The practical and emotional sustainability of your caring role
- Your willingness and ability to continue to provide this support

The carers’ assessment must also look at:

- The impact of your support needs on your own health and wellbeing
- Caring responsibilities you may have for a child, or children, or any other person you may provide care for
- Your ability to work; access education or training or engage in recreational activities
- What outcomes you wish to seek to achieve in your daily life
- Whether support could help you achieve these outcomes
• Whether the adult, your support network and the wider community can contribute towards meeting the outcomes you want to achieve

• Whether you or the person you are caring for would benefit from preventative support or information and advice.

Any carer who appears to have a need for support as a result of providing care to another adult should be offered a carers assessment by the council. You do not have to be living with the person you care for, or be caring full time. A carer is entitled to an assessment regardless of the amount, or type of care provided, your financial means or your level of needs for support. You are entitled to carers assessment whether the person you care for has had an assessment of their needs from adult social care, or if they have been assessed as not being eligible for support.

The carers assessment is not a test and there are no right or wrong answers. In preparation for the assessment, it is useful to give yourself some time to think about how caring affects you. You should also think about what help would make a difference to you as a carer, in continuing in your caring role (if this is what you wish). This preparation will help you when discussing things which the council must consider when doing your carers’ assessment.

In preparation for a carers assessment you will be provided with information about the assessment in advance, this includes a copy of the assessment and information about the type of questions you will be asked during the assessment.
It may be useful to write some notes for yourself, or talk to family or friends to help you think about your needs.

Following a carers assessment a carers support plan will be produced. This is a summary of your support needs and the services that you could be provided with if you are an eligible carer.

Depending on eligibility these may include:

- Access to a “flexible breaks scheme”, where a paid carer gives you a break for a few hours – this service is not means tested, but is dependent on the level of care provided

- A “carer direct payment”, where the carer receives a single payment to help them in their caring role.

If you are currently caring or expect to become a carer in the future and feel you may have needs as result of providing this care you can contact:

**Dudley Carers Network directly on 01384 818723 or email carers.network@dudley.gov.uk to discuss your options for assessment.**

Alternatively, if you or the person you care for has a named social worker or health care worker you can contact them to request a carers needs assessment.
Dudley Carers Alliance

Dudley Carers Alliance is a partnership of Dudley borough organisations (including Dudley Council, Dudley CCG, Dudley Group of Hospitals, voluntary and other organisations) that provides a one stop shop for carers. Expert information, advice and guidance are available to support and empower all carers, irrespective of age or circumstance.

Help on offer includes:

Financial help and options for practical support
Support with getting time to yourself
Advice on keeping healthy and well
Support to feel less stressed
Guidance on planning for the future

The Alliance aims to provide a voice for carers, to influence policies which affect their lives and the people they care for and to always ensure that the rights of our carers at the top of all agendas.

Contact the Alliance on 01384 818723
Keeping safe and independent at home

Staying safe and independent at home is crucial to us all. In Dudley borough there are a number of ‘prevention’ services on offer which work to keep older people safe, well and as independent as possible in their homes.

There are also additional services which you may want to use to provide extra support to the person with dementia. These include:

- Home care
- Day care
- Community meals
- Community transport
- Residential or nursing home care for short periods of respite.

Your Dementia Advisor or Nurse can help you find out more information on services like these.
Living well feeling safe

Living well, feeling safe is a partnership service, offering older people living across Dudley borough, practical safety, security and wellbeing advice, in their own home.

The service offers older people a complete safety and security advice and support service. Practical and preventative safety, security and wellbeing advice and information, along with practical help is on offer.

On request, an officer will visit you in your home, to give advice, assistance and practical support on a range of home security, personal safety and wellbeing needs.

The Living well, feeling safe service is ideal for anyone who is feeling vulnerable, isolated, in need of support or simply is concerned about their home’s safety or their own personal safety. Advice and support services are offered on such things as the council’s home safety and security service (which includes keysafes and door access systems), home and personal alarms, sheltered and supported housing options, falls support and advice, home improvement help and adaptations, handyperson service and fire safety advice.

A free home assessment or further advice is available by calling 01384 817743
Dudley Telecare Service

Telecare represents the whole range of ‘assistive technology’ products, which include all sorts of alarm systems. The products provide support to people in their own homes, through their link to the Dudley Telecare Service.

The telecare products are unobtrusive and flexible and represent an automatic monitoring service, which can and has transformed the lives of people who wish to remain living independently for as long as they possibly can. The products also bring reassurance to users and carers by ensuring their safety within the home.

Dudley Telecare Service is Dudley Council’s emergency telecare call service. It operates 24 hours a day, 365 days a year. A range of telecare solutions can be installed in the home and these are linked to the emergency monitoring service.

Here professional and experienced call handlers, who are specifically trained to respond to customers emergency requirements, take calls either direct from customers or make response calls to customers which are triggered by the alarm products, checking if help or assistance is required. In this way customers, their family and friends have constant reassurance that help and support is always at hand.
Telecare equipment is installed in the home, following an assessment of the customers’ needs and is tailored to each individual’s requirements.

Devices on offer include simple pendant alarms, gas detectors and safety taps which shut of gas or water supply, bogus caller alarms, pill dispensers, falls detectors, extreme temperature detectors, movement sensors, door alarms, as well as specialist packages tailored to the needs of people with dementia – which can provide real independence. These packages include electronic location devices which let carers know if people have left the room or home. These can include GPS technology that can locate people who have left the home and become lost or disorientated.

Find out more by calling Dudley Telecare Service on 0300 555 2040
Dudley Falls Prevention

Dudley Falls Prevention offers advice, support and practical help to anyone concerned about falling.

The service offers a range of support to adults who are worried about their mobility and are concerned they may fall, or have already taken a fall.

A doctor of nurse can refer to the service, or people can refer themselves by contacting the service directly.

A falls advisor or falls nurse will look at reasons the person may be stumbling or falling and will find ways of preventing falls. Minor aids to improve mobility may be provided; referrals can be made to a handyperson to arrange minor home repairs or adaptations to make the home safer; medication will be assessed; other helpful services can be provided and if suitable the service can enrol people onto a twelve week exercise programme – to improve balance, strength, mobility and confidence. The aim is to keep people mobile, strong and independent.

Call the service to ask for help on 01384 814459
Enabling Community Support

Enabling Community Support provides a range of practical help, advice and support to older people, aged 60 plus, in their homes. It is intended for people who live at home but who need a little extra support to live independently, happily and successfully.

A tailored assessment and support plan will be produced for each person. This will state how often support officers will visit, for how long and what help and support will be provided to help the person.

The service aims to improve the quality of life, happiness, health and wellbeing of older people living in the community. Support provided might help to improve a person’s health, hygiene and wellbeing, their financial situation and money management, confidence, address loneliness, develop independent living skills or provide support to meet a person’s spiritual or faith needs.

The service also offers a useful holiday visiting service, when family members are away.

The service can be contacted by calling 01384 818359
Help at home

If practical help in the home is needed - with personal care needs such as:

- getting up and going to bed
- washing and dressing
- help with toileting
- preparing meals

Please contact the council’s Access to adult social care team for advice and, if appropriate, a referral for a social care assessment.

The Access to adult social care team is made up of experienced social workers and customer services officers who offer advice and information about the full range of social and community activities and not just those traditionally associated with social care.

The team will arrange for a needs assessment to be undertaken. They will also discuss with you all of the options available to help you and signpost you to other services if required.

Contact the team on 0300 555 0055.
**Assistance with meals**

People who require assistance with their meals can request a social care assessment from the Access to adult social care team.

**Delivered meals**

If you wish to make your own meal arrangements, there are a number of local and national commercial organisations offering to deliver meals. Take a look at the Dudley Community Information Directory for ‘meals provision’. If you are able to get out but need help with shopping, the directory has details of which shops will offer help.

**Visit www.dudleyci.co.uk**

**Social centres/luncheon clubs**

There are a number of lunch clubs across the borough. These are organised by volunteers and meals are provided. The clubs offer not just a lunch but a social opportunity too. See the full list on the Dudley Community Information Directory.
Driving

Receiving a diagnosis of dementia is not necessarily a reason to stop driving immediately. People with dementia may be able to drive safely for some time. However, as dementia progresses it may have an effect on the ability to continue to drive safely.

Informing the DVLA

If a diagnosis of dementia has been made, it is a legal requirement to inform the Driver and Vehicle Licensing Agency (DVLA). The DVLA will ask permission to contact the person’s GP or consultant to obtain a medical report. This information is used to make a decision on whether they can continue to drive. In some cases they may also ask the person to undergo a driving assessment.

A driving assessment is an overall assessment of the impact the dementia is having on driving performance. It will test things like reaction time and visual skills and will include an on road driving session in a duel-braking car. If the DVLA decides that a person can continue to drive a new driving licence will be issued for a limited period, usually a year, and will then be reviewed.

Informing the insurance company

The insurance company must also be informed of the diagnosis, as failing to do so could jeopardise the policy.
Useful courses

There are a number of courses available for carers living in Dudley borough.

They focus on providing information, useful hints and tips, practical knowledge and skills, and (perhaps most importantly) confidence to help support the caring role. They are also a great opportunity to get out the house for a few hours and chat to other carers who may be in similar situations.

**Carer Information and Support Programmes (CrISP)**

These are four week programmes, so that carers can understand dementia as it progresses and gain ideas for coping and supporting the person with dementia. There are two separate programmes; CrISP 1 is for relatives/friends of people within the first year of diagnosis and CrISP 2 is for those who have been living with dementia for two years or more.
CRiSP 1 has four weekly sessions. Subjects covered include:

- What is dementia?
- Finance and legal matters
- Caring for someone with dementia
- Looking after yourself and next steps

CRiSP 2 has four weekly sessions. Subjects covered include:

- What is dementia?
- Understanding the changes occurring as dementia progresses
- How to access more help as dementia progresses
- How to live as well as possible as dementia progresses

Contact Alzheimer’s Society on 0121 521 3028 to register.
Carer Aware (online course and information toolkit)

This is an online course for carers to find out about their rights, along with information and support options. Find out:

- Who is a carer
- What are your rights
- What support is available in the Dudley borough
- Where to find further information

Test your knowledge and get a formal certificate and accreditation.

Visit www.dudley.gov.uk/carer

Looking after Me (expert patient programme)

Looking after Me is the carers’ version of the Expert Patient Programme (EPP) which is for anyone with a long term illness and disability. This is a self-management course for adult carers with long-term health problems including stress and tiredness. It aims to help carers to learn new coping skills, develop the confidence to take more control of their life and meet with others who share similar experiences. Carers need to commit to one, three hour session a week for six weeks. Some courses are open to all carers; others focus on carers of people with a specific illness or disability

Call 01384 816 437 or email smp@dudley.gov.uk for dates and venues.
Financial help

Charging for services

There may well be a charge for services provided to the person with dementia.

The amount they will have to pay will be dependent on their income, benefits, savings and capital. This will be worked out during a financial assessment which the council will arrange after they have completed a social care assessment. The outcome of the financial assessment will be shared and any charges to be made will be made clear. There is no charge for these assessments and any questions, worries or concerns can be discussed with the allocated social care worker.
Benefits

Attendance Allowance/Personal Independence Payment (PIP)

Attendance Allowance is a benefit for people aged 65 and over, and PIP is a benefit for people under the age of 65, who need help with tasks due to illness or disability. The person with dementia may be entitled to this if they require help with things such as making a meal, washing, getting dressed, taking medication on time, or if you need to supervise them with tasks. They don’t need to be actually getting the help from someone else at the time of applying. These benefits are not means tested, so are not dependent on savings or income, and they are tax free.

If the person with dementia is in receipt of any benefits, or a pension, but is unable to manage the money themselves, you can ask to become an “appointee” so that you can manage this for them. This is arranged through the Department of Work and Pensions.

If someone goes into hospital for more than 28 days, their Attendance Allowance will be affected - contact the Department of Work and Pensions for advice.
Council Tax Disregard

If the person with dementia is in receipt of either Attendance Allowance or PIP, they may be entitled to a reduction in council tax known as a “disregard”. This results in a 25% reduction for two people living in a property, and an exemption for someone who lives alone. It is not means tested. The form needs to be signed by their GP and then sent with a copy of the benefit letter to the council tax office. The bill will then be re-calculated. For an application form contact the council or ask a Dementia Advisor.

Carers Allowance

To get Carer’s Allowance you must meet all the following conditions:

• You look after someone who gets a qualifying disability benefit
• You look after that person for at least 35 hours a week
• You earn £100 a week or less (after deductions).
• You satisfy UK presence and residence conditions
• You are aged 16 or over
• You are not in full-time education

The qualifying disability benefits include:

• Disability Living Allowance at either the middle or highest rate for personal care needs
• The daily living component of Personal Independence Payment (at either rate)
• Attendance Allowance (at either rate); or
• Constant Attendance Allowance (of the normal maximum rate) paid with the Industrial Injuries or War Pensions schemes. If your state pension is more than £59.75 then you will not be paid the Carer’s Allowance. However, you should still claim if you receive other means-tested benefits, as you may get extra money with these if you’re a carer.

If you have a break from caring for more than 28 days (e.g. the person is in hospital) Carer’s Allowance may be affected – contact the Department of Work and Pensions for advice.
Legal issues

When someone is diagnosed with dementia it is important that they are given the opportunity early on to plan for (and in doing so retain some control over) their future.

This ‘advance care planning’ allows the person to make decisions ahead of time which will guide how they are cared for at a time when they lose the capacity and to tell others what they want. Anyone can discuss advance care planning with their GP free of charge.

Advance care planning can include the following:

**Advance Statement**

A simple record of wishes and preferences. This might include where a person wants to be cared for in the future, particular spiritual needs, favourite foods, music, personal care preferences etc.

**Advance Decision to Refuse Treatment**

A legally binding record of refusal or limits to treatments. This can include a decision about refusing resuscitation.
Lasting Power of Attorney (LPA)

It’s important to consider how the affairs of the person with dementia will be managed in the future, if they become unable to make decisions for themselves.

A Lasting Power of Attorney is a legal document that allows a person to choose someone (the attorney) to make decisions on their behalf if they lack the capacity to make those decisions themselves in the future. There are two types of LPA, and people can make one or both.

Property and Financial Affairs LPA

A Property and Financial Affairs LPA allows someone to make decisions about things like:

- Selling or buying property
- Paying the bills
- Collecting benefits
- Allowing access to information about the person you care for
Health and Welfare LPA

A Health and Welfare LPA allows someone to make decisions about things like:

• Where the person should live
• Consent to medical treatment
• The daily routine, what you should eat or wear for example

An LPA can be set up so that the person can only make decisions on limited things, or it can cover everything. It can only be used once it has been registered with the Office of the Public Guardian. An LPA is only valid if the person has the mental capacity to set this up.

Deputyship

If the person with dementia is no longer able to make the decision themselves to set up an LPA, and you need to manage their affairs, you will need to apply to become a court-appointed deputy.

For Information about making an LPA or applying to become a deputy contact:

Office of the Public Guardian PO Box 15118 Birmingham B16 6GX

Tel: 0300 456 0300

Email: customerservices@publicguardian.gsi.gov.uk
www.publicgaurdian.gov.uk
Continuing care at home

**Purchasing care help privately**

Even if the person with dementia doesn’t currently meet the eligibility criteria, or if their income and savings are too high, the council, or a Dementia Advisor can still provide you with information on local agencies to help you purchase care and support privately and help you make the best choice for you.

**Respite care**

Respite care for short breaks usually takes place in a residential or nursing home and can either be self-funded, where the person pays the costs themselves, or can be wholly funded or part-funded by the council.
Alternatives to caring at home

There may come a time when you feel you just can’t go on providing the level of care needed at home by the person you are looking after. As a carer your own health may not be good, your personal situation may have changed or the health of the person with dementia may have deteriorated so that you can no longer continue. Take time to consider the needs of both of you. If possible talk things over together and fully explore all practical options. Could you move house? Have more help in the home? Extra respite? It can help to talk to someone who isn’t directly involved, perhaps outside the family such as a Dementia Advisor, friend, your doctor or social worker or a voluntary agency.

You may eventually have to make the extremely difficult decision that the person with dementia would be best looked after in a residential or nursing home. Try not to feel guilty or that you are shirking your responsibility. Sometimes though, it can feel like bereavement.

Give yourself credit for all you have managed. See it more as a change in caring arrangements, in which you can still share a vital part in caring and supporting. In fact, once you are no longer being constantly tired and busy with practical tasks, you may find you have more quality time to share together.
Residential care

Many older people live in specialist retirement homes. These homes provide live in care. They must be registered with the Care Quality Commission (CQC)

Residential homes – provide 24 hour care, with support for personal care. They also provide social activities, trips out and meals. They are not legally required to provide trained nursing help. Increasingly these days residential homes are run by private companies, or the voluntary sector. All homes have to be registered with the council and are inspected regularly.
Nursing homes – provide 24 hour nursing care and there has to be a registered nurse on duty at all times. Most are run by private organisations.

Choosing a home

When choosing a care home make sure that you visit several potential homes and take a family member or friend along. It takes time and careful consideration to choose the right home. Talk to other people, professionals and a Dementia Advisor.

When you visit a home take a good look around. Ask questions about the home, staffing levels, atmosphere and social activities. The council offers a useful booklet ‘Arranging and paying for residential and nursing home care’ which covers key points and has a useful checklist of things to consider when choosing a home. This is available on request from the council’s Access team – call 0300 555 0055 to request a copy.

Care home providers are required to provide information about the fees and terms of a person’s proposed stay; this is called a statement of purpose. They should also provide their most recent CQC inspection report and a copy of their complaints procedure.

The council will provide a list of care homes both in Dudley borough and other neighbouring boroughs that they will fund placements in. This is available again on request on the above telephone number. It is particularly important to contact the council before you make any care home arrangements that the council may be completely or partially funding.
If you wish to look at homes with which Dudley Council does not have a contract, you can look in the Dudley Community Information Directory (www.dudleyci.co.uk) or on the CQC website (www.cqc.org.uk). Alternatively an independent local organisation (which works in partnership with the council) called Safe and Settled can help you with the care options process (www.safeandsettled.co.uk, tel 07768 126548) or you can look at some of the independent information provided by Independent Age, Age UK England and NHS Choices – their details are listed at the back of this booklet.

**Financing residential care**

The councils Access team can provide information and advice about the costs of residential care. Following a social care assessment and separate financial assessment the council will provide advice on residential care options and whether the person concerned will have to pay none, part, or all of the costs.

Depending on the person’s income, capital and savings they may not qualify for funding support from the council for their residential care. If they have capital or savings, including property, over the upper capital limit of £23,250 they will have to pay the full cost of their care. In this case they are known as a ‘self-funder.’
If you have a property the rules for self-funding and assistance that the council can provide can be quite complicated. It is possible that certain types of capital and savings or property could be disregarded and it is in everyone’s best interests to ask for a financial assessment; the council can then advise on the individuals own particular circumstances.

Self-funders are still entitled to the same free and detailed help and advice in working out their needs and finding the right care for them.

Safe and Settled again offers alternative care advice and support service for people who are self-funders.

If you are a carer you should note that the person you care for's move to a care home could affect your benefits. If you are not the cared for's spouse your rights to remain living on in the home may be affected. If you are not sure, seek legal advice.

**Feelings and emotions**

When the person you have been caring for moves into some form of permanent care, you, the carer, will probably experience many complicated and perhaps unexpected feelings. Sadness can be mixed with relief and you could feel guilty about this. Relieved or not, it is an enormous change. You may feel very lonely and find it difficult to fill your day. Give yourself time to adapt.
Near end of life care

Caring for a person with dementia can be a journey that lasts months, or for many years.

Over that period you may need to consider a range of care and support options in order to ensure that the person with dementia and yourself receive the best care possible at each stage along the way.

As the person you are caring for nears the end of their life a range of support is still on offer to ensure that all concerned are supported. Dudley’s dementia gateways continue to offer end of life support to people with dementia, their families and carers. They work closely with palliative care services and can call upon support from these as required. The gateways also offer on-going care, support and counselling for family members and carers at this distressing time.

Dementia Advisors will facilitate ‘difficult conversations’ between carers, family members and loved ones. They often make it possible for people with dementia to remain independent in their community for longer, avoiding hospital admissions and for them to die at home if this is their wish.
Life after caring

It is always a shock when someone close to you dies, even when they have been ill for a long time, or have been in a residential or nursing home. As well as having to cope with all sorts of emotions, you will also have to sort out practical arrangements. If possible, try to get a relative or a friend to be with you and help you.

Information sheets can be obtained about “What to do when someone dies?” You can get these from organisations such as the DWP, Carers’ UK, Age UK, the Citizens’ Advice Bureau, CRUSE, and many undertakers.

Developing a new life

Building a new life may take time. You will probably feel tired for a long time, as your body tries to catch up with the pressures you had as carer. If you are worried, chat to your GP or practice nurse.

Some people will want to start or go back to work. There are many schemes to help people brush up on skills or acquire new ones. Contact your local Job Centre or local education colleges.

Alternatively, voluntary work can lead to new interests and friends; contact your local volunteer bureau.

Over the years, carers often lose contact with their friends and it is difficult to start again. You may have to make the first move.

Joining a club or group can be a way in. Think back to any interests or hobbies you had, or perhaps dreamed about doing! You can contact your library for a list of local groups or search on the internet.

Give yourself time and choose what is right for you.
Useful contacts

Admiral Nurses
www.hacw.nhs.uk/admiralnurses
Call 0808 802 8080

Admiral Nurse Direct
Call 0800 888 6678

Age UK England
Call 0800 678 1174
www.ageuk.org.uk
Support and services for people with dementia and their carers

**Age UK Dudley**
3 Dudley Court North, The Waterfront, Brierley Hill. DY5 1XP
Call 01384 354508
www.ageuk.org.uk/dudley

**Alzheimers Society**
Call 0121 521 3028/0121 521 3020
www.alzheimers.org.uk

**Carers UK**
Adviceline 0808 808 7777/020 7378 4999

**Care Quality Commission**
Citygate, Gallowgate, Newcastle upon Tyne. NE1 4PA
www.cqc.org.uk
Call 03000 616 161

**Cruse Bereavement Care**
Call 01902 420055
Email: dudleywolves@cruse.org.uk
www.cruse.org.uk

**Citizens Advice Bureau Dudley**
Marlborough House, 11 St James’s Road, Dudley
West Midlands. DY1 1JG
Adviceline 03444 111 444
e-mailadvice@dudleycabx.org
CADAL@dudleycabx.org
www.citizensadvice.org.uk
Department of Work & Pensions
Attendance Allowance Call 0345 605 6055
Personal Independence Payment (PIP) Call 0800 917 2222
Carers Allowance Call 0345 6084321
Pension Credit Call 0800 991234

Dudley Carers Network
Call 01384 818723
Carers.network@dudley.gov.uk

Dudley Community Information Directory
www.dudleyci.co.uk

Dudley Council Access Team
Call 0300 555 0055

Dudley Council Dementia gateways
Brett Young Gateway (Halesowen) 01384 13600
Crystal Gateway (Brierley Hill) 01384 813315
www.dudley.gov.uk/dementia

Dudley Council Enabling community support
Call 01384 818359

Dudley Council for voluntary services (DCVS)
Call 01384 573381
www.dudleycvs.org.uk

Dudley Falls Prevention
Call 01384 814459
Support and services for people with dementia and their carers

Dudley Telecare Service
Harbour Buildings, Waterfront West, Brierley Hill. DY5 1LN
Tel: 0300 555 2040

DVLA
Monday to Friday 8.00am to 5.50pm
Saturday 8.00am to 1.00pm
Swansea SA99 1TU
Call 0300 790 6806
www.gov.uk/dementia-and-driving

Elderley Accommodation Counsel – First Stop
Care options and independent advice
Call 0800 377 7070
www.eac.org.uk

Independent Age
18 Avonmore Rd, London W14 8RR
Call 0800 319 6789
www.independentage.org.uk

Living well feeling safe
Call 01384 817743

NHS Choices
www.nhs.uk
Office of the Public Guardian
PO Box 16185, Birmingham. B2 2WH
Call 0300 456 0300
customerservices@publicguardian.gsi.gov.uk
www.publicguardian.gov.uk

Regional Driving Assessment Centre
Monday to Friday 8.30am to 4.30pm
Unit 11 Network Park Industrial Estate, Birmingham. B8 1AU
Call 0845 337 1540
www.rdac.co.uk

Relatives and Residents Association
Information and support to people helping their loved ones move into a residential home
Call 0207 359 8136
www.relres.org

Safe and Settled
68 Jacobs Hall Lane, Great Wyrley, Walsall. WS6 6AD
07768 126548
hello@safeandsettled.co.uk
www.safeandsettled.co.uk

White House Cancer Support
The White House, 10 Ednam Road, Dudley. DY1 1JX
Call 01384 231232
info@support4cancer.org.uk
Your notes

Your Dementia Advisor: ..........................................................

Your GP: ..............................................................................

Your Admiral Nurse: ...........................................................

Your Alzheimer Society contact: ............................................
Help Beat Dementia

Sign up to the new national service connecting you to the latest dementia research. Vital studies into early diagnosis, prevention and new treatments for dementia are making progress - that’s why more volunteers are needed. By joining you will be registering your interest in taking part in national dementia research. This helps people with dementia, their carers, or anyone interested in dementia research to be matched to studies.

Please contact
www.joindementiaresearch.nihr.ac.uk
Or call Alzheimer’s Research UK
0300 111 5 111