# **DEMENTIA TOOLKIT**





## CONTENTS

- **3** Introduction
- 4 How we support dementia carers
- 11 Dementia assessments
- 12 Blue Badge
- 13 Power of Attorney
- 14 Carer Assessments
- **16** Prevention Assessment Teams
- 17 Continuing Health Care
- 18 West Sussex Care Guide
- 19 Carers Health Team
- 20 Finding support
- 25 Residential care
- 27 Respite
- 30 Minority carers
- 35 Dementia courses and groups
- 37 Bereavement and living grief
- **39** Dementia friendly communities
- 40 Numbers and contacts

Caring for someone with dementia can be emotionally and physically demanding. Sometimes called 'crowded isolation' because a carer can feel so alone with the person they are caring for and yet so busy organising services and coping with everyday living needs.

Everyone's journey is different which is why we offer individual guidance and information to help you in your caring role. Once you are registered with Carers Support West Sussex we are able to help with a host of support, ranging from emotional to financial assistance tailored to your needs as well as refer you to partner organisations.

This toolkit will help you navigate the services and support available to people caring for someone with dementia in West Sussex, how and who to go to for help and how we can support and guide you.

### INTRODUCTION



We offer a wrap-around service to carers, including emotional support, one to one discussions around your needs, signposting and referrals to relevant services as well as access to our monthly online dementia carer groups, skills training, carer events and help with accessing funding and grants.

Our dedicated web page offers details of our services. Visit www.carerssupport.org.uk/dementia. Our monthly dementia carers newsletter will keep you up-to-date with all that is happening locally. Just email us at info@carerssupport.org.uk or call 0300 028 8888 if you'd like to be added to the mailing list.

### **Carer Wellbeing Fund**

As a carer registered with us, you may be eligible to apply for a non means-tested grant from our Carer Health and



Wellbeing Fund. The money from the fund can be used flexibly on purposes which would enhance a carer's health and/or wellbeing; for instance, gym or swimming sessions, breaks away, massage and de-stressing therapies.

### **Carer Equipment Service**

The Carer Equipment Service is available to you as a registered carer to access equipment and assistive technology. The primary aim is to help maintain and enhance independence and give peace of mind in your caring role. We will assess the individual needs unique to you and the person you care for. It is our position to be there for you in every way possible, helping improve independence, safety and wellbeing. Details of our equipment can be found on our website at www.carerssupport.org.uk/carer-equipmentlist. The team are also able to provide a bespoke service to research creative equipment solutions to meet unique requirements.

### **HOW WE SUPPORT DEMENTIA CARERS**



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This is a free service which can fund or part fund your equipment needs. If you would like to find out about your options, please contact us.

#### Telecare/Technology Enabled Care (TEC) service

Technology Enabled Care allows you to call for help in the event of an emergency, if you're not feeling well or if you're anxious about a situation, such as an unknown caller to your home. There are various alarms, sensors and equipment which can suit a variety of needs and offer reassurance to you. NRS Healthcare offer free installation and equipment for 6 weeks for residents with short term immediate needs, i.e.to avoid a hospital admission; and/or where there is evidence that a referral will delay or reduce more costly input.

If you have longer-term needs you may receive your service for free for longer.

#### **Emotional support services**

The role of a carer can be an emotional struggle as well as being physically challenging.

Our counselling service is a psychological talking therapy in place to offer support to carers of family and friends. It is an opportunity to talk about problems, emotions, and issues in a secure safe and confidential environment. Speaking with a professional counsellor offers an independent and nonjudgemental alternative support.

Our counsellors offer one-to-one counselling sessions either online or telephone. There are up to 6 sessions available to each carer.

### HOW WE SUPPORT DEMENTIA CARERS

## HOW WE SUPPORT DEMENTIA CARERS

#### **Contingency Planning**

As carers we like to think that we will always be there when needed but sometimes this is not possible. This could be for many reasons, including becoming unwell, a domestic or family emergency or changes to your usual work routine, such as a need to travel away from home/work base.

A Contingency Plan is there so that the person you are caring for is supported at the earliest opportunity and you have peace of mind that there is something in place.

Download our contingency planning form on our website at www.carerssupport.org.uk/contingency-planning.



#### **Benefits advice**

A recent Carers UK survey revealed that 68% of carers regularly use their own income or savings to pay for care or equipment for the person they care for. It may improve

your financial situation if you have an understanding of the benefits you are entitled to. We offer a one to one benefits service. Find out more and book an appointment with our adviser at www.carerssupport.org.uk/carer-benefits-adviceservice

### **Digital champions**

If you feel you are missing out on all you should because you do not have access or are not confident about using the internet you can ask for support from one of our digital champions, who will gently support you to get access and gain confidence for shopping, online meetings and other services you would like to use. Contact us and ask to be referred to a champion.



#### **Carer Emergency and discount card**

You may be concerned as to what will happen to someone you provide care and support to, should you be involved in an accident or be suddenly taken ill yourself.

Our Carer Emergency Contact Card (CECC) offers peace of mind to family and friend carers and supports them to develop a carer contingency plan in case of an accident or an emergency.

The card also doubles up as a carer discount card, giving carers a range of exclusive offers and discounts within West Sussex. Apply for your card at www.carerssupport.org.uk/ carer-emergency-card



The West Sussex memory assessment service – sometimes called MAS - provides early detection, diagnosis, treatment and care if you or someone you care for have problems associated with dementia. If you are worried that you or someone you care for may be developing a dementia please visit your GP and discuss your concerns with them initially. With your permission they should do a brief memory test and if needs be will make a referral to MAS for an assessment.

Part of the MAS assessment would ideally involve a CT brain scan. Although most referrals come directly from a GP or other GP surgery, staff such as nurse practitioners, other health and social care professionals can also refer. Paramedics and social workers can also refer. MAS also work in partnership with dementia advisors through the Alzheimer's Society.

### How do I find out more?

- Contact your local GP surgery for a memory test
- Find out more about MAS at www.sussexpartnership.nhs. uk/service-memory-assessment-service
- Assessment process and tests www.alzheimers.org.uk/ about-dementia/symptoms-and-diagnosis/diagnosis/ assessment-process-tests

### **DEMENTIA ASSESSMENT**

### **BLUE BADGE**

Blue badges are for people with severe mobility problems who need to park close to where they are going. This can apply to many people living with dementia, which can affect balance, co-ordination and spatial awareness.

- Apply online at www.westsussex.gov.uk/roads-and-travel/ parking/blue-badge-scheme-and-disabled-parking/ apply-for-or-renew-a-blue-badge/
- For a postal application call 01243 777653
- · More information www.alzheimers.org.uk/blog/howapply-blue-badge-person-dementia





A lasting power of attorney is a legal document that allows someone to make decisions for you, or act on your behalf, if you're no longer able to or if you no longer want to make your own decisions.

- www.ageuk.org.uk/information-advice/money-legal/legalissues/power-of-attorney/
- www.nhs.uk/conditions/dementia/legal-issues/
- · www.dementiauk.org/get-support/legal-and-financialinformation/lasting-power-of-attorney/
- See top tips on Power of Attorney from local solicitor lan Macara on our YouTube channel at www.youtube.com/ watch?v=4iB0odAOHsl&

## **POWER OF ATTORNEY**

### **CARER ASSESSMENTS**



#### **Carer's assessment**

If you provide unpaid care to a relative, friend or neighbour you are entitled to an assessment of your needs even if the person you care for has not had their needs assessed and is not receiving services from West Sussex County Council. The assessment is free of charge and carried out by Carers Support West Sussex. Details at www.carerssupport.org.uk/ carer-assessments

#### **Needs Assessment**

If you think you or the person you care for needs social care support you have the right to ask West Sussex County Council to assess your needs. An assessment helps identify your social care needs, what's important to you and what you want to be able to achieve.

This does not mean funding will be provided at the end of the assessment as you may not be eligible for this but if you are not eligible an assessment can help you plan and buy your own support.

The assessment is free of charge and WSCC will aim to complete it within 28 days of you contacting them and will involve discussing your circumstances, focusing on the issues that are important to your circumstances to: • work with you to identify what you want to achieve • look at your strengths and capabilities • identify support that may be available in your local community that could help you remain as independent as possible and prevent any further deterioration of your

- needs.

#### Find out more

- publications/your-life-your-choice/introduction/
- · www.independentage.org/information/advice-guidesfactsheets-leaflets/paying-for-your-care.

### **CARER ASSESSMENTS**

www.westsussexconnecttosupport.org/adult-social-care-

### **PREVENTION ASSESSMENT TEAM (PAT)**

PAT teams are multi-agency, multidisciplinary teams delivering a preventive service across West Sussex. The team includes health advisors (qualified health professionals); social care workers and support workers from the voluntary sector who can advise over the telephone or come and see you in your own home. The service is for adults and older people who might not be eligible for other statutory services and who have unmet physical, psychological, social, functional and/or environmental needs.

#### **PAT South**

Tel: 01273 268900 Email: aaw.pat@westsussex.gov.uk

**PAT West** Tel: 01243 642370 Email: pat.west@westsussex.gov.uk



**PAT North** Tel: 01403 229510 Email: pat.north@westsussex.gov.uk

Some people with longterm complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS continuing healthcare.



www.nhs.uk/conditions/social-care-and-support-guide/ money-work-and-benefits/nhs-continuing-healthcare/

#### More information

The process involved in NHS continuing healthcare assessments can be complex. An organisation called Beacon gives free independent advice on NHS continuing healthcare. Visit the Beacon website at www.beaconchc.co.uk or call the free helpline on 0345 548 0300.

## **CONTINUING HEALTH CARE**



### WEST SUSSEX CARE GUIDE

West Sussex Care Guide will help you to find information about how to live well at home, care and support services and care homes.

You can view the Care Guide online at www2.westsussex.gov. uk/socialcareandhealth/adults/careguide2021/flipbook/index. html

Print copies of the guide are available in your local library.



The Carers Health Team are a team of health professionals who aim to promote the health and wellbeing of carers. They are a free service providing support for carers over the age of 18 registered with a West Sussex GP. They work directly with carers and will develop individual strategies for each carer with an aim to reduce the strain of coping with their caring role. They may, if it is necessary, also look at the health needs of the person who is being cared for.

They work closely with other NHS specialist services, social & caring services and voluntary & community services and will link carers with these services when appropriate.

They can provide information and advice on specific health conditions, as well as practical advice on the caring environment (safe lifting and handling, healthy eating, risk minimisation).

Call 01243 623521, email SC-TR.carerwellbeing@nhs.net or visit www.sussexcommunity.nhs.uk/services/carers-healthteam/108921

### **CARERS HEALTH TEAM**

### **FINDING SUPPORT**

#### **Dementia Connect**

Dementia Connect, from Alzheimer's Society, is a personalised dementia support service which provides people affected by dementia with the support they need, when they need it, by phone, online and face to face. Dementia Connect is for people with all types of dementia, with a diagnosis or pre-diagnosis. As well as carers, family or friends of someone who has dementia. Once someone has been referred, they will continue to receive support for as long as they need.

Call 0333 150 3456 for phone support, available:

- Monday Wednesday: 9:00am 8:00pm
- Thursday Friday: 9:00am 5.00pm
- Saturday Sunday: 10:00am 4:00pm

Online support is available 24-hours a day at www.alzheimers.org.uk/dementiaconnectfaq

The Alzheimer's Society's guide to caring for someone with dementia is available at www.alzheimers.org.uk/publicationsabout-dementia/the-dementia-guide-other-languages

Talking point is the Society's online forum to share with other carers. Visit www.alzheimers.org.uk/get-support/dementia-

talking-point-our-onlinecommunity

We can refer you to the Alzheimer's Society for more support – just call 0300 028 8888

#### **Dementia UK**

Looking for information or advice about dementia or Alzheimer's? Call the Dementia Helpline for free on 0800 888 6678 for support from its dementia specialist Admiral Nurses. The Helpline is open from 9am to 9pm Monday to Friday and 9am to 5pm on Saturday to Sunday. We can refer carers whose GP surgery is in the Crawley, Horsham and Mid Sussex CCG area to an Admiral nurse.

#### Age UK

AGE UK West Sussex Brighton and Hove offer a wide range of services including home help, telephone befriending, help with form filling, meal deliveries and wellbeing advice. Visit www.ageuk.org.uk/westsussexbrightonhove/

## **FINDING SUPPORT**



### **FINDING SUPPORT**

If you'd like to access any of the services above or have any questions about activities near you, need information or advice, or if you're worried about a friend or family member, please contact 0800 019 1310 or email info@ageukwsbh.org.uk

#### Sage House

Dementia Support at Sage House in Tangmere is a community hub for dementia designed to enhance the wellbeing and quality of life for local people living with dementia, their family and carers.

Sage House is a bespoke, modern and functional community centre, where people can access the most up to date support, information and advice.



They offer Wayfinding to help guide families through their personal dementia journeys, as well as day care, a range of activities for those living with dementia and their carers, therapy rooms, a salon, a smart zone, and a café. Visit www.dementiasupport.org.uk/about-dementia-support or call 01243 888691.

#### **Know Dementia**

Know Dementia is a Sussex-based charity providing advice and support to people living with dementia and their family members/carers. Much of the support is provided through Memory Moments Cafes, Sporting Moments sessions and Singing and Musical Moments. Visit knowdementia.co.uk/ west-sussex-moments/

### **Cognitive Stimulation Therapy**

Age UK West Sussex Brighton and Hove is running courses helping people with dementia live well and fight back against the condition's progress. Each course supports eight people, runs for six months and offers a range of activities which work on motor skills, memory and movement.

The approach (called Maintenance Cognitive Stimulation Therapy) has been proven to slow the progression of

### **FINDING SUPPORT**

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dementia and the benefits appear to be comparable to those offered by dementia medication.

If you think you or a friend/family member might benefit from joining this course, please email cst@ageukwsbh.org.uk

#### **Worthing Dementia Hub**

Worthing Dementia Hub is a new local hub opening at 46 Goring Road, Goring-by-Sea, offering a range of services to people in the area. Visit www.dementiafriendlyworthing.org/



#### Carewise

Carewise provides expert information and advice on paying for care. Visit www.carewiseadvice.com/

### The Alzheimer's Society

The Alzheimer's Society provides a guide to deciding on care home support at www.alzheimers.org.uk/get-support/helpdementia-care/care-homes-who-decides-when

### The Relatives & Residents Association

The Relatives & Residents Association is the national charity for older people needing care and the relatives and friends who help them cope. Call 0207 359 8136 (Monday to Friday 9.30am-1pm, and Thursdays 6-8pm), email helpline@relres. org or visit relres.org.

#### **Elderly Accommodation Counsel**

Elderly Accommodation Counsel (EAC) is a national charity that aims to help older people make informed choices about meeting their housing and care needs. Visit www.eac.org.uk/

#### **Care seekers**

Care seekers help people find the right care at the right price for them. Visit www.careseekers.co.uk/

### **RESIDENTIAL CARE**

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#### Healthwatch

Healthwatch is the independent champion for people who use health and social care services in West Sussex. They focus on ensuring that people's worries and concerns about current services are addressed. Visit www.healthwatchwestsussex. co.uk/

#### **Independent Age**

Independent Age offers a range of support, including this factsheet on settling into a care home: www.independentage. org/information/advice-guides-factsheets-leaflets/settlinginto-a-care-home

#### My care matters

Whether you care for people at home, in a care home, hospital or hospice, you can use My care matters to improve that experience. A person who may not be able to express their needs, or someone on their behalf, creates a short and simple profile of their non-medical needs, preferences, likes and dislikes which can be used by health and social care professionals in any care setting to deliver dignified and person-centred care. Visit profile.myfuturecare.org/

#### TuVida

TuVida provide help and support to carers and the people they care for across West Sussex. Services include day centres and groups, carer respite, and short break weekends for people with dementia and their family or friend carers. Visit www.tuvida.org/westsussex

#### West Sussex Care Guide

Find local care at www2.westsussex.gov.uk/ socialcareandhealth/adults/careguide2021/flipbook

#### Sage House

Sage House offer dementia day breaks. See www.dementiasupport.org.uk/day-breaks



### RESPITE

### RESPITE

#### **Care Seekers**

Care Seekers will help you find the right package of care for you either at home or in residential accommodation – a useful guide for self-funders. Visit www.careseekers.co.uk/ careseekers\_care\_search.shtml

#### Carepoint

If you are eligible for a package of care from your local authority this may contain respite options. This will be agreed with you as part of a needs assessment.

#### **Guild Care Worthing**

Guild Care Worthing runs a range of dementia support services in Worthing. Visit www.guildcare.org/Pages/ Category/dementia-support



#### Age UK

Age UK Daybreak services operate across towns in West Sussex – details at www.ageuk.org.uk/ westsussexbrightonhove/ourservices/dementia-support/

#### **Chestnuts Day Centre**

Chestnuts Day Centre in Bognor Regis Provides a specialist service for adults with physical disabilities, Alzheimer's and other related dementias who have a moderate to substantial need of support or supervision. Visit www.nhs.uk/services/servicedirectory/chestnuts-day-centre/ N10500608

#### The Chichester Lunch Club

A friendly and supportive environment for adults, generally older people, living with mental health problems, dementia and mild cognitive impairment. We also welcome and offer respite for carers giving them the opportunity to shop or take a break while their loved ones are cared for in a safe environment. Visit www.chichesterlunchclub.org.uk/

#### **Tapestry Day Clubs**

Support for people who are living in isolation, feel socially excluded or experiencing a deterioration in memory. Visit www.tapestrydayclub.co.uk/

### RESPITE



### **MINORITY CARERS**



Black, Asian and **Minority Ethnic** dementia carers See this range of leaflets in various languages for dementia carers who are Black, Asian or Minority Ethnic: www.tide. uk.net/resources/bameresources/

The Alzheimer's Society guide for dementia carers

comes in a wide range of languages. See www.alzheimers. org.uk/publications-about-dementia/the-dementia-guideother-languages

Meri Yaadain (My Memories) was set up to make a meaningful impact in supporting people from Black Asian Minority Ethnic (BAME) communities who face barriers in accessing information, services and advocacy. Visit www.meriyaadain. co.uk/

The Black Dementia Company is a UK based service that was

set up with the aim of meeting the needs of persons living with dementia and their friends, relatives and care-givers across the world, including, and especially, persons living with dementia from the global African and Caribbean community. Visit theblackdementiacompany.com/

Tapestry is a multi-cultural group for Black, Asian and mixed parentage families and individuals who live in Worthing and surrounding areas Visit www.facebook.com/ **TapestryWorthing** 

Asian language mental health helpline 0808 800 2073

**Gypsies and Traveller dementia carers** 

Saying it as it is – experiences of Gypsies and Travellers caring for a family member living with dementia. Visit www.dglg.org/ uploads/2/4/7/5/24756021/saying\_it\_as\_it\_is\_june\_2021.pdf

More info at www.gypsy-traveller.org/

#### LGBT+ dementia carers

Dementia is challenging for everyone, and everyone's situation will affect what living with dementia is like for them. However, being LGBT+ and having or caring for someone

### **MINORITY CARERS**

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with dementia can present extra difficulties. It's important to know that you aren't alone. Support and advice is available, there are services and care settings designed to support you, and the law protects your rights to equal treatment and privacy. By knowing your rights, finding the right support, and planning for your future, it is possible to live and care well for someone with dementia.

Find out more:

- www.alzheimers.org.uk/get-involved/bring-dementia-out
- www.alzheimers.org.uk/get-support/daily-living/lgbtliving-dementia
- www.openingdoorslondon.org.uk/appeal/lgbt-dementiasupport

### Learning Disability dementia carers

A person with a learning disability is less likely to receive a timely diagnosis of dementia because changes in the person are attributed to their learning disability and 'behaviours', rather than being seen as a potential health condition like dementia. Find out more and see resources and support at www.macintyrecharity.org/our-expertise/resources/gettinga-timely-diagnosis-of-dementia-wellbeing-for-life/

#### Young Onset dementia carers

Neil's Club for those with young onset dementia offers a service from 10am-4pm, every other Thursday. Location: Alternates between: Balcombe Social Club, Balcombe and The Beech Hurst Haywards Heath. Cost: £36/session (+ cost of lunch). For details email westsussex@tuvida.org or call 01903 790270.

A West Sussex group for people with early onset dementia meets virtually via Zoom. For further details please contact Tim Wilkins at tim.wilkins@alzheimers.org.uk or call 07801 136212.

Young Dementia Network: www.youngdementiauk.org/ south-east

The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. Whilst

### **MINORITY CARERS**



### MINORITY CARERS

## **DEMENTIA COURSES & GROUPS**

not young onset specific, many of the DEEP groups are well attended by younger people with dementia. Visit www. dementiavoices.org.uk/

Tide (together in dementia everyday) offer a number of online groups to help keep carers connected. Their UK-wide young onset carers group meet (virtually) on the first Tuesday of every month at 10am. They provide a safe space for family carers to share their experiences. The group is free.

More information at www.youngdementianetwork.org/newsand-events/our-webinars/



See our website for details of our online dementia carer groups and sign up for our newsletter to receive details of other face to face events. Visit www.carerssupport.org.uk/ dementia

Tide offer online carer groups for a chance to meet up with other dementia carers – as well as specific groups for carers. The charity also offers training for carers in, for example, speaking up for yourself and self-care. Visit www.tide.uk.net/ online-learning-events/

Dementia Carers Count - provide free courses designed and delivered by healthcare professionals, that will help you develop skills and build confidence to navigate the highs and lows. Learning how to make your life manageable and maintain your own health and well-being is vital when you're caring for someone with dementia. They will give you practical tips that you can use every day.



### **DEMENTIA COURSES & GROUPS**

### **BEREAVEMENT & LIVING GRIEF**



DCC also give you the opportunity to meet and connect with people in a similar situation. Visit dementiacarers.org.uk/ virtual-carers-centre/

#### **Dementia Adventure**

Many carers feel they are doing what anyone else would in the same situation – looking after their mother, husband, wife or friend and just getting on with it. Caring can be immensely rewarding but it can also take up a huge amount of time and energy and it's hard to find the time to take care of your own well-being or find the support you need. Dementia Skills Sessions and Nature is Calling programme helps equip you to meet the challenges you face with support Visit dementiaadventure.co.uk/what-we-do/training-andconsultancy/friends-and-family/ Feelings and behaviours of grief and bereavement are very much permitted and accepted in society when there is loss of life. The common assumption is that they only occur when there has been a death. When caring for someone with Dementia you can experience feelings of grief and bereavement when the person is still living. When someone is still living you are told "Be Strong" and encouraged to suppress these feelings as an action of bravery, strength or staying positive.

There is little awareness, acknowledgment or understanding about feelings of grief and bereavement when a person is still living – but when you care for someone with dementia, loss does not just mean loss of life. Find out more about the free courses offered by dementia charity tide at

Practical information to help when someone dies: www.advicewestsussex. org.uk/dying-mattersweek-2021/

www.tide.uk.net/events/



### **BEREAVEMENT & LIVING GRIEF**

### **DEMENTIA FRIENDLY COMMUNITIES**



West Sussex Libraries has a list of many resources and support sites for those in bereavement at arena.westsussex.gov.uk/ web/arena/currentoffer/bereavement-support

Find out more about our workshops and our monthly former carer group at www.carerssupport.org.uk/bereavement-workshops

Find your local Dementia Action Alliance to see how they are working to create a community response to supporting people living with dementia and their family and friend carers.

Visit www.dementiaaction.org.uk/south\_east



### NUMBERS AND CONTACTS

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#### **Carers Support West Sussex**

0300 028 8888 www.carerssupport.org.uk/dementia

Alzheimer's Society Dementia Connect Support Line - 0333 150 3456 (7 days)

Dementia UK Admiral Nurse Helpline 0800 888 6678 (7 days)

**Dementia Support** Sage House Tangmere - 01243 888691

**Relatives and Residents Association** 0207 359 8136

Independent Age Helpline 0800 319 6789

**Carers Trust** is a major charity for, with and about carers. It works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Its vision is that unpaid carers count and can access the help they need to live their lives. Visit carers.org/

**Carers UK** provide information and guidance to unpaid carers. This covers a range of subjects, including your rights as a carer in the workplace and how to complain effectively and challenge decisions. Tel: 0808 808 7777 from Monday to Friday, 9am – 6pm or email advice@carersuk.org

Age UK West Sussex Brighton and Hove offer a wide range of services from respite for carers, home help, meal deliveries, money support and much more. Visit www.ageuk.org.uk/ westsussexbrightonhove/

**Sage House** in Tangmere offer Wayfinding to help guide families through their personal dementia journeys, as well as day care, a range of activities for those living with dementia and their carers, therapy rooms, a salon, a smart zone, and a café. Visit www.dementiasupport.org.uk/

**Age Well** provides a range of tips and information, to help you stay well, healthy and independent when growing older in West Sussex. Visit www.westsussex.gov.uk/campaigns/agewell-in-west-sussex/



