DEMENTIA TOOLKIT

Carers Support
West Sussex

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INTRODUCTION

Caring for someone with dementia, even if it's undiagnosed, 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.

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 the webpage here: Carers Support Dementia
Our quarterly dementia carers newsletter will keep you up-to-date with all that is happening locally. Just email us at info@carerssuport.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 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

From time-to-time, carers find themselves at a loss as to what would help them in their caring situation, and for some, small items of equipment can make a significant difference. On this page, you will find a list of equipment that may provide an innovate solution for your caring role. Most items are low cost, and you can easily find them by looking online. If you are interested in applying for the equipment listed on this page Equipment Service and would like further information, please contact us via our helpline or email us.

This is a free service which could 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. NRS Healthcare

Carer Coaching Is It For You?

Unlike a more traditional support, which emphasises emotional support and information exchange, coaching-based programmes will help you to identify and achieve your own goals and provide you with specific tools, strategies, and skills to improve your resilience, well-being, and feelings of control. While there may be some similarities, coaching is not the same as counselling, therapy, advice, advocacy or training.

"I have done a few things differently since being part of the programme. I am less argumentative and more relaxed about letting things go. I have walked away rather than rushing straight in things. I know I feel calmer – a lot calmer." – Carer who completed the coaching programme.

The carer coaching programme to date, has helped over 50 carers to redevelop positive self-belief, re-enforce resilience and recognise resourcefulness, whilst taking steps towards re-prioritising their own wellbeing. Have a look here: Carer Coaching

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.

HOW WE SUPPORT DEMENTIA CARERS

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: 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: Benefits Advice Services

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 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. Apply for your card at 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 here: Memory Assessment Service
- Assesment Process and tests

Blue Badge and Driving

Blue badges may be for people with dementia who need to park close to where they are going due to non-visible disabilities which are now part of the eligibility criteria.

Apply online for your Blue badge

For a postal application call 01243 777653

For more information visit:

Alzheimers how to apply webage

Drivers with dementia must tell the DVLA and their insurer straightaway. Find out more about UK law on driving with dementia, here: Driving and dementia | Alzheimer's Society

Lasting Power of Attorneys (LPAs)

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.

There are two types of LPA you can set up: one for making financial decisions and another for making health and care decisions. An LPA for health and care decisions can only be used if you lose mental capacity. An LPA for financial decisions can also be used, with your permission, while you still have mental capacity – but you need to choose this option when setting it up. You can only create an LPA if you have mental capacity to do so and you haven't been put under any pressure to set it up. An LPA isn't necessarily permanent. You can cancel it at any time while you have mental capacity.'

Power of attorney – Setting up a lasting power of attorney (LPA) | Age UK

Carer 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 us.

Carer Assessments | Carers Support West Sussex

PREVENTION ASSESSMENT TEAM (PAT)

Preventative Assessment Team

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.

You can contact the team : Monday to Friday from 9am to 5pm.
Phone: 0330 222 4222.
Email : prevention@westsussex.gov.uk
Visit: Prevention Assessment Team

CONTINUING HEALTH CARE

NHS Continuing Health Care

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

NHS continuing healthcare can be provided in a variety of settings outside hospital, such as in your own home or in a care home. Find out more here: 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.
Helpline: 0345 548 0300
Visit: Beacon CHC | Free advice & expert representation - Beacon CHC

CARERS HEALTH TEAM

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 visit carers in their own home at a time to suit their needs and 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.

CARERS HEALTH TEAM

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.netor
Visit : https://www.sussexcommunity.nhs.uk/patients-and-visitors/services/carers-health-team

CARE NEEDS ASSESSMENTS

Care Needs Assessments

If you think you need social care support, you have the right to ask WSCC to assess your or the person you care for needs. An assessment helps us identify your social care needs, what's important to you, and what you want to be able to achieve. They can only provide funded social care support to those who are eligible. Most people have to pay for some or all of their own care.

A Self-assessment is designed to help you think about what is working well for you and what needs to change.
A friend, relative or carer can also complete a self-assessment form on your behalf.

Or you can ask them to send you a paper copy.

Once you have completed it, you can either: keep it for your own personal use or send it to them to provide background information about your personal circumstances, and they will contact you about a formal assessment.

Assessment by the County Council:
You have the right to ask WSCC to assess your or your cared for's needs if you think you need social care support. The assessment is free of charge.

The simplest way to request an assessment is to complete the online form: Adult social care assessments

FINDING SUPPORT

Dementia UK

Looking for information or advice about dementia or Alzheimer's? Call the Dementia telephone 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.
Home - Dementia UK

Age UK

AGE UK West Sussex Brighton and Hove offer a wide range of services including home help, telephone befriending, help with form filling depending on your locality, and wellbeing advice. Visit: Age UK Brighton & Hove

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

Carers Trust

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. Carers Trust | Transforming the lives of carers

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: Dementia Support or call 01243 888691.

Carewise

Carewise provides expert information and advice on paying for care. Visit: Carewise

The Alzheimer's Society

The Alzheimer's Society have a wealth of information that answers questions such as "Do you have to sell your house to pay for care?" Alzheimer's Society | Get Support

They provide people affected by dementia with the support they need, when they need it, by phone, online and face to face. 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.
Find support they offer locally to you here: Support near you

Carers UK

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.
Call: 0808 808 7777 from Monday to Friday, 9am – 6pm
Email: advice@carersuk.org
Visit: UK | Carers UK

Care Rights UK

Everyone has legal rights about how they should be treated by health and care services. Knowing and using their rights can help ensure the person cared for receives good care.
www.carersuk.org/help-and-advice/practical-support/what-are-your-rights-as-a-carer/

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. Healthwatch West Sussex

Independent Age

Independent Age offers a range of support, including this factsheet on settling into a care home:
Independent Age | Fact sheet

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. The profile enables the whole person to be taken into account by all those caring for and interacting with them.

It is free for individuals to create a Mycarematters profile. They also work with hospitals and care homes to incorporate Mycarematters profiles into the everyday life of all wards and care homes caring for people who may have communication challenges, either as a result of a cognitive impairment such as dementia or a temporary condition such as delirium.
Visit : Mycarematters profiles - Mycarematters 2020 CIC

RESPITE

TuVida

TuVida provide help and support to carers and the people they care for across West Sussex. Services include a day centres, carer respite, and short break weekends for people with dementia and their family or friend carers. The respite service is self-funded and provided at an hourly charge and are available in slots of two hours or more.

Subsidised services may be available for six hours of respite care per week plus a 10 hour night sit once weekly. For eligibility details, please contact them.

The emergency respite service is funded entirely by West Sussex County Council – meaning there is no associated cost to carers. The service is available subject to staff availability and funding, according to the terms of the contract with West Sussex County Council. For availability, please contact them. Visit: TuVida

West Sussex Care Guide

Find information about care and support services and homes in West Sussex. West Sussex Care Guide

RESPITE

Guild Care Worthing

Guild Care Worthing runs a range of paid for dementia support services in Worthing.
Visit: Services for older people | Guild Care

Daybreak Respite

The Daybreak Respite service provides day support for people living with dementia, which includes stimulating and meaningful activities to promote confidence and social interaction. The service also provide much needed respite to carers. All refreshments and a two-course lunch provided.

Locations: Bognor Regis, Littlehampton, Storrington, Horsham, Crawley, Haywards Heath, Brighton and Burgess Hill.

Details here: Daybreak Respite

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 Chichester Lunch Club

Tapestry Day Clubs

Helping people with early-stage dementia live independently for as long as possible.

Included in the day are all refreshments, a two- course, home-cooked lunch and optional memory-boosting activities tailored to the interests of individual guests. The hosts are carefully vetted and fully trained. Transport is generally available.
Visit Dementia Care | Tapestry Day Club | Sussex & Surrey

Tapestry is a multi-cultural group for Black, Asian and mixed parentage families and individuals who live in Worthing and surrounding areas.
Visit: Tapestry Facebook

The Alzheimer's Society

The Alzheimer's Society guide for dementia carers comes in a wide range of languages including Bengali, Urdu, Hindi and Gujarati.
Visit: Alzheimer's Languages

UCL Brain Sciences'

UCL Brain Sciences' Have iSupport for South Asian Dementia Carers which is an online, self-directed, educational programme for people looking after someone with dementia in Bangla, Punjabi and Urdu: South Asian Dementia Carers | UCL Faculty of Brain Sciences

Dementia UK- Specialist Dementia Admiral Nurse Clinics'

The Black, African and Caribbean Communities Admiral Nurse clinics offer appointments with a dementia specialist Admiral Nurse for people from Black, African and Caribbean communities who are living with dementia, and their families. This is an opportunity to seek free expert, confidential, culturally sensitive dementia support and advice.
Visit: Black, African and Caribbean Communities Admiral Nurse clinics - Dementia UK

MINORITY CARERS

Gypsies and Traveller dementia carers

Please contact the Friends, Families and Travellers helpline on 01273 234 777.
They are open: Monday to Friday From 10.00am to 4.30pm.
Closed on Bank Holidays.
Support for Carers - Friends, Families and Travellers

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 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.

Pride in Ageing: Living well with dementia – LGBT Foundation

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

https://www.dementiauk.org/information-and-support/health-advice/learning-disabilities-and-dementia/

Young Onset dementia carers

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.

Support and information is available through Young Onset Dementia UK'

Rare Dementia Support

Support is available for rarer types of Dementia from Rare Dementia Support.

Tide

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 fourth Monday of the month at 7PM – 8PM. They provide a safe space for family carers to share their experiences.
https://www.tide.uk.net/young-onset-carers-group/

Tide also 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/events/

Dementia Carers Count

Dementia Carers Count provide free courses designed and delivered by healthcare professionals, that will help you develop skills and build confidence. 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. DCC also give you the opportunity to meet and connect with people in a similar situation. Visit dementiacarers.org.uk/virtual-carers-centre/

Bereavement and Living Grief

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.

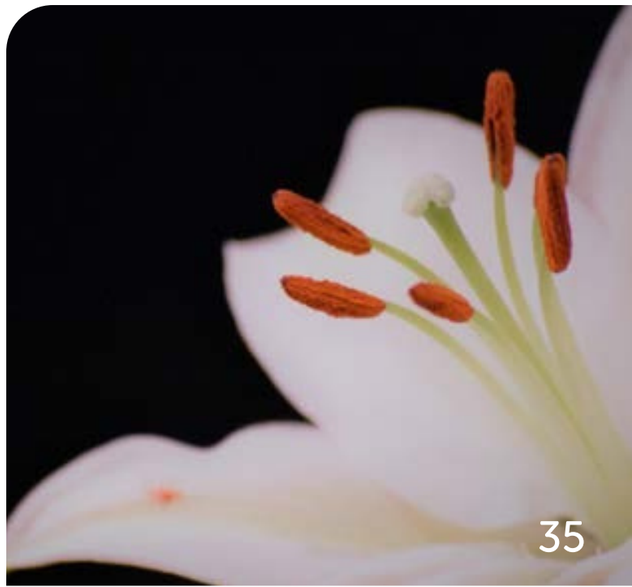
There is little awareness, acknowledgment or understanding about feelings of grief and bereavement when a person is still living – but when you care for someone with dementia, loss does not just mean loss of life.

More reading here: Dementia Care Grief and Loss

TIDE - Together In Dementia Everyday - Living Grief and Bereavement

West Sussex Libraries has a list of many resources and support sites for those in bereavement at:

West Sussex Libraries Bereavement Support



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