

BURGESS HILL

LOCAL DEMENTIA SUPPORT

Dementia is a term given to a group of symptoms from certain diseases which affect the brain. Alzheimer's disease is the most common cause of dementia. In the UK, there are about 850,000 people living with dementia.

The symptoms of dementia are progressive and on an unknown time scale, which can be hard to accept. It could be months or many years before the symptoms become advanced. On a positive note, many people with dementia can live full lives with little or no assistance. Living in the present, doing the fun things now which were planned for later in life is a strategy which helps some people cope with this condition.

Burgess Hill Dementia Action Alliance

Burgess Hill Dementia Action Alliance supports the local community and businesses to become Dementia Friendly, so they are better prepared and equipped to support those living with dementia, as well as raising general awareness of the condition and how to support those affected by it.

The Alliance aims to raise awareness through Dementia Friends Sessions, community and business events and general discussion of the needs of those living with dementia and their loved ones to best continue playing a full and fulfilling part in their community.

If you would like to get involved you would be very welcome to join the Alliance. For further information, email Rachelhbeckett@gmail.com

Safe Havens

There are 5 Safe Havens in Burgess Hill town centre, located at:

- Market Place Shopping Centre
- Waitrose
- The Martlets Shopping Centre
- Burgess Hill Town Council's Help Point at 96 Church Walk
- Burgess Hill Library.

The Safe Havens provide a quiet place for people affected by dementia to receive help and assistance, for example, help with orientation, transport information or locating a mislaid person or belongings.

Dementia Friends

Dementia Friends Champions provide free dementia awareness training sessions for the local community. Contact local Dementia Friends Champions Colin Holden on 07710 908050, email colinholden15@btinternet.com, or Rachel Beckett on 07447 477755, email Rachelhbeckett@gmail.com.

A staff member at West Sussex County Council's Library Service is also a Dementia Friends Champion and runs free information sessions for local groups and businesses. Contact 01293 651751 or email clair.stanton@westsussex.gov.uk.

Information and advice

Alzheimer's Society provides information and support, funds medical and social research, and campaigns for better quality of life for people with dementia and greater understanding of the condition. Support in West Sussex includes support groups, advice and guidance. Dementia Support Workers offer information and practical guidance, face to face, over the phone or in writing, to help people understand dementia, cope with day-to-day challenges and prepare for the future. The Dementia Adviser service offers information about all aspects of living with dementia and supports people to access services. People with dementia and their carers can contact a Dementia Adviser whenever they need further information or support to find other services. Contact 01403 213017 or visit the website www.alzheimers.org.uk.

Alzheimer's Society Sussex Helpline provides a wide range of quality information for people with dementia, carers, family, friends and health professionals. Topics include getting a diagnosis, types of dementia, emotional and practical support, legal and financial information, and choosing a care home. Contact 01403 213017 (Monday to Friday 10am - 4pm) or email sussex.helpline@alzheimers.org.uk.

National Dementia Helpline is a national service run by the Alzheimer's Society providing information, advice, support, and signposting to other appropriate organisations. Callers speak to a trained Helpline Adviser and calls are confidential. Contact 0300 222 1122.

Talking Point is a live, online support community run by the Alzheimer's Society for people with dementia and their carers, family and friends to discuss all aspects of the condition. It's open 24-7, and is a safe place to ask questions, share your experiences and receive advice and support. Visit www.forum.alzheimers.org.uk.

Dementia UK provides specialist dementia support for families through its Admiral Nurse Service. When things get challenging or difficult for people with dementia and their families, Admiral Nurses work alongside them, giving the one-to-one support, expert guidance and practical solutions people need. Contact Admiral Nursing Direct Dementia Helpline on 0800 888 6678 or visit www.dementiauk.org.

Know Dementia is a local charity providing advice and support for people who have been diagnosed with dementia. Contact 01273 494300, email info@knowdementia.co.uk or visit www.knowdementia.co.uk.

Social & support groups

Neil's Club is for people with young onset dementia run by Crossroads Care South Central. It offers age appropriate support, activities and outings for younger people with dementia. The club meets every Wednesday from 10am – 4pm, alternating between The Beech Hurst Harvester in Haywards Heath and Balcombe Social Club. Contact 01903 790270 www.crossroadscare-sc.org.

Haywards Heath Family Support Group is for people living with dementia or affected by dementia. It provides an opportunity to meet other people in the same situation, to find out more about dementia and where to get help, friendly support and advice. Meets every 2nd Monday of the month from 7 – 9pm, at the Beech Hurst Harvester Restaurant, Butlers Green Road, Haywards Heath. Contact 01273 494300.

De-Café is an evening group for people living with dementia, their carers, friends and family. It runs at Age Concern's Pauline Thaw Centre in Dale Avenue, Hassocks, on the 3rd Wednesday of each month, from 6 - 8pm. The café provides a social evening in a safe environment, with light bites and sometimes live entertainment. It also provides an opportunity to meet others in a similar situation, to talk and learn from each other, and to receive support and advice from staff and volunteers of the Alzheimer's Society. Contact 01403 750485 or 07720 948990.

Meeting Point welcomes people living with dementia and their carers to drop in for refreshments and chat each Saturday, from 10am – 12pm, at the United Reform Church, Junction Road, Burgess Hill. Contact 01444 244458.

Forget Me Not Café for people living with dementia and their carers runs at St John's Church in the town centre. The café is held fortnightly on Mondays, from 2pm - 4pm. Light refreshments are available plus an opportunity to chat with other people. Activities include 'jog your memory' time listening to music, chair keep-fit, reminiscing with pictures and art all taking place in a safe, relaxed environment. Contact 01444 230499 or email stjohnsbh.admin@icloud.com.

Sally Anne's Memory Lane Café will start in April, once a month initially, at the Salvation Army Hall in Cyprus Road. The café will be for people living with the early stages of dementia and their carers. It will be a morning of live music and fun filled nostalgia, all shared with light refreshments. Contact Envoy Dawn Shearn on 07900 996287.

Sunday Moments provides an opportunity for people living with dementia and their carers to meet up informally for a Sunday walk and refreshments. Contact 01273 494300.

Respite care

Crossroads Care South Central provides a tailored service of respite support for carers across West Sussex including an emergency respite scheme. Contact 01903 790270 or email admin@crossroadscare-sc.org.

Forest View Care Home in Burgess Hill provides respite day care facilities from Monday to Friday for 20 people living with dementia, and 10 people on Saturday, with lunch provided. Contact 01444 245749 or email forestview@shaw.co.uk.

Villa Adastra in Hassocks provides day care facilities from Tuesday – Friday for eight people living with dementia, with lunch provided. Contact 01273 842184.

The Elderberry Club offers a carer-focused respite service providing an opportunity for carers of people with dementia to take some time for themselves, knowing the people they care for are in a safe, stimulating environment. Lunch and refreshments provided, transport possibly also available. Held on the 2nd and 4th Saturday of the month, from 10.30am – 4pm at The Redwood Activity Centre, Perrymount Road, Haywards Heath. Contact 07840 652054 or email elderberry@ageukwestsussex.org.uk.

See also *Neil's Club* (details above) run by Crossroads Care South Central.

Support for carers

Burgess Hill Carers Support Group is a peer support group run by the Alzheimer's Society, giving carers the opportunity to meet with others in a similar situation. Run by a facilitator, the sessions offer a change to ask questions, get information and share experiences in a safe and supportive environment. Carers and the person they care for can also attend the

group, which meets at The King's Church, Victoria Road on the first Wednesday of each month, from 1.30 – 3.30pm. Contact 01403 213017.

Carers Support Group at Villa Adastra, Hassocks run by Carers Support West Sussex. Meets on the 1st Thursday of each month (except public holidays), from 2 - 3.30pm. Contact 0300 028 8888 or email info@carerssupport.org.uk.

Carers Support West Sussex provides information and support for friends, families and partners of people with a long-term health condition including memory loss and dementia. They have a support worker for dementia carers in the area who can provide one-to-one support if needed. Contact 0300 028 8888 or email info@carerssupport.org.uk. The Carers Response Line on 0300 028 8888 is open 9am – 5pm Monday to Friday, 9am – 7pm on Wednesdays and 10am – 12pm on Saturdays.

Neighbourly Care is a support and befriending charity run by volunteers providing practical help to people of all ages experiencing or caring for someone with illness, frailty, disability, social isolation or a sudden crisis. Neighbourly Care volunteers can offer company and a chat over a cup of tea, shopping for someone or with them, changing light bulbs, writing a letter, simple DIY jobs, or light gardening. Contact the Helpline on 07876 066368.

Carers Emergency Alert Card is a credit-card sized laminated card which will identify you as a carer if you are out alone and become ill or have an accident. Registering with the scheme provides information about the person you care for and the names of two people who can be contacted in an emergency. The scheme is free of charge to West Sussex residents. For further information visit www.chichestercareline.org.uk or telephone 01243 778688.

Library Services

Burgess Hill Library is a Dementia Safe Haven and members of staff have been trained as Dementia Friends. The Library provides the following resources:

Memory Management Library Card is for people living with dementia so they can borrow books and other items with no fines charged if they are returned late. It is also free to borrow audiobooks with this card.

Reading Well Books on Prescription for dementia recommends books that might be helpful if you have dementia, are caring for someone living with dementia or would like to find out more about the condition. The books provide information and advice, support for living well, advice for relatives and carers, and personal stories.

Reminiscence packs – for people living with dementia, their memories from years ago often remain detailed and intact. Recalling these memories can be immensely therapeutic and enjoyable. The Library has a Reminiscence Collection of packs and books, including the Pictures to Share books. The packs are on themes including the 1950s, 1960s, Baking, General, Household, Seaside, Transport, Washday and World War II.

Pictures to Share – reminiscence tools including song lyrics.

Housebound Reader Service - for people living with dementia or their carers who are unable to visit the library but would still like to enjoy reading or listening to books. Volunteers select, deliver and return library books to people who are unable to go to the library themselves.

Alzheimer's Society Drop-ins - the Library also holds drop-ins with the Alzheimer's Society. Contact 01444 255452 for information about forthcoming dates.

Travel

The *Helping Hand Card* is a new scheme being operated by local bus companies including Brighton & Hove Buses, Metrobus, Southdown PSV, Compass Travel, Stagecoach, Big Lemon and Sussexbus. The free card enables passengers who may need extra assistance to discreetly explain the help they may require without having to verbally communicate it.

The card will display simple advice to help the passenger/customer, such as "Please wait until I am seated", "Please help me count my change", "Please be patient if I am confused." Further information and an application form can be found www.buses.co.uk or by calling 01273 886200.

Airports can be busy and confusing at the best of times. If you have dementia then these feelings are amplified many times and the airport can become bewildering. The Alzheimer's Society produces a factsheet with tips and advice about planning a holiday for people affected by dementia, including arranging travel insurance. www.alzheimers.org.uk.

Gatwick Airport can provide a special lanyard for passengers to wear while at the airport. This will identify them to staff as someone who may need additional support or understanding. Members of staff have been specially trained to recognise the lanyards and act accordingly.

Lanyards can be obtained at one of the Assistance Reception areas, even if you haven't requested or need special assistance. Gatwick Airport has also produced a booklet, *Making Your Journey Easier*, where you can find detailed information on what to expect on your journey through the airport to help you prepare. For further information, email hidden.disability.at.gatwick@ocs.co.uk.

Dementia Awareness Week

Dementia Awareness Week is held annually in May. Information about local events will be available on the Town Council's website and social media.

Each year 'Remember the Person' is the recurring theme for Dementia Awareness Week. People are encouraged to 'remember the person' behind the dementia; the person is more than the dementia. Even at an advanced stage, people with dementia sometimes indicate they are aware of those around them; they are still 'there'.