WELCOME PACK



A dementia diagnosis is not the end of the road, life continues and there is still so much to be enjoyed. You are still the same person, even with any difficulties you may experience. The important thing is to focus on the things that you can still do and enjoy, and it will help you to stay positive. You'll be amazed at what you can do once you put your mind to it. And as a student who has been working with the SUNshiners for a few months now, I can definitely say that I have been amazed and proud of the projects that they have worked on over the years. It is so inspiring to see them achieve so much as a group, as well as the things they have accomplished in their personal lives, which all go against the stigma around living with dementia. With that being said, we have put together this welcome pack of things that you can do to keep yourself active and stimulated. Remember to just have a go and see what you enjoy!

Mary – Psychology student

The SUNshiners are a group of people living with dementia who come together to support each other and work to raise awareness of dementia, as well as tackle stigma surrounding dementia. This also gives them the opportunity to meet and socialise with other people living with dementia where they can discuss similarities or challenges that they face.

If you are inspired by the SUNshiners, you can find out more about them here:

https://www.kmpt.nhs.uk/get involved/service-user-andcarer/living-withdementia/sunshiners/



Here are some personal messages from some of our members

I had a new beginning, it happened in 2018. In that year I made many decisions, small ones and big ones too. I decided that I would retire at the age of 57. I'd worked all my life and now I wanted to do things for me. A new car with new controls to learn. Buying a touring caravan, learning the new skills that we needed to set it up and those needed to pack it up again. I joined new groups and made new friends, in one of those groups we devised a survey, online and in hard copies, something I had never done before! A singing group, I've not sung in a group since my school days. Another group offered a poetry project and I joined, also, having not written poetry since my school English classes. What an experience, I thoroughly enjoyed it. Together with the group we produced a book. Such an amazing feeling to have my poetry published. Oh, by the way, in June 2018 I was diagnosed with early onset Alzheimer's. Life is for living.

Written by B.R - Feb 2021 (Female)

Don't give up just because you have been diagnosed with dementia, you can still do things and learn even if at first you can't recall things. Perseverance is the key. You will get frustrated and tired, have a rest then go back and try again the next day. Keep hold of your hobbies, even if you have to relearn them. Your concentration will be minimal to begin with but it will strengthen over time. I have had dementia for 5 years now, was diagnosed when I was 45, and I didn't think I would be doing so much now when I first got diagnosed. I have learnt a few new hobbies in lockdown, I do courses because I enjoy learning at the time although I can't remember much of any course I do. It doesn't matter. Last thing I would say is: Be kind to yourself.

Written by T.S – Feb 2021 (Female)

People living with dementia are often told that they cannot learn new things, but that is far from the truth. Here are some of the SUNshiners' achievements!

One of our members is a qualified tour guide! This required them to complete exams, including a theory and practical! And they passed with an amazing score of 99.4%!!



Congratulations! You have now completed the International Tour Guide Certification Program! Your program score, including exam and video evaluation, is 99.4 %.

Your certificate and pin will be presented to you by DEINUK. <u>Please</u> <u>confirm your name as you would like</u> <u>it to be printed on your certificate.</u>

We'd love to hear your thoughts on the course – did you like it? Did you find it useful? Please send us your thoughts.

Great Job!

~ The Tour Guide Excellence Team www.tourguideexcellence.com

Some of our members took part in a 'Dreams and Visions' project which consisted of people with a dementia diagnosis being supported by students and community volunteers to create short films based on the scripts they had written. This included using dramatic improvisation and acting.

Click the link to see how this went:

https://vimeo.com/253024240

One of our other members is undertaking a diploma in English literature. They have a whole list of courses they want to pursue! Although they find it difficult at times, they are certainly still enjoying it.

Here are some links to free courses you may be interested in:

https://alison.com/

https://www.open.edu/openlearn/freecourses/full-catalogue





Diploma in English Language and Literature - Revised Certification 8 Learn different English writing styles and aspects of English literature with this free English language course. Mobile Friendly English Free Course Yes This free online course in English Language and Literature will give you a fascinating overview of the English language and its cultural Publisher 血 XSIQ treasures. English is not just useful, but also rich in history and literature. By taking this short course, you will learn about some of 0 Accreditation the most important writers, poets, and playwrights in the history of CPD English. This will be a fascinating journey of discovery, so why wait? Start learning, today.



The SUNshiners were involved in a poetry project called 'Time and Place' which has been made into a book and published! If you would like to purchase a copy of Time and Place Collected Poems, it is available through Amazon and Waterstones. Below is a picture of the book launch!

For more information on their project, please visit this site: https://www.dementiavoices.org.uk/time-and-place-poetry-project-2020/

Maybe you would like to express yourself through writing poetry or reading some. Here is a poem written by one of our members!

MY DEMENTIA JOURNEY

My Dementia diagnosis, well where do I start? The words pierced like a dagger through my heart. They don't know what they're talking about, my first reaction, but the more I thought about it, and on reflection, was I just kidding myself with my illusions, by ridiculing the diagnosis and Doctor Dalvi's conclusions? I've included them to give a balance to this little rhyme. my long term memory's fine, you must give me my due, but what happened yesterday, I haven't a clue! With an uncertain future that fills me with dread, terrified about the plaques building up in my head. With a cure for Dementia still to be found, here's hoping they find one while I'm still around. I wonder is this just another phase in life's long journey my world now filled with phrases like 'Power of Attorney'? At 'Sunshiner's 'we discuss our conditions and how it affects

while we are still able and compos mentis.

The announcement of a cure would be really sublime, In fact the perfect ending to this little rhyme.

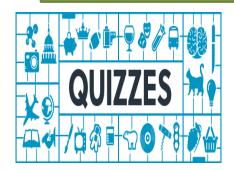






How about having some fun by doing quizzes or even writing your own? One of our members has kindly come up with a quiz that you can complete!

(Answers are at the end of the pack!)





NATURAL WORLD QUIZ

- 1. Can you name Steptoe's horse please? ANSWER:
- 2. What type of animal is an Ibex? ANSWER:
- 3. This bird related instrumental was a hit for Fleetwood Mac? ANSWER:
- 4. Herman Melville wrote this book about a Great White Whale? ANSWER:
- 5. These birdies, the Eagle and the Albatross figure in which sport? ANSWER:
- 6. A pipistrelle is a form of what? ANSWER:
- 7. This bird is associated with cricket? ANSWER:
- 8. Hazel, Fiver and Bigwig are fictional rabbits, but where is their fictional home? ANSWER:
- 9. What country is the home of the Giant Panda? ANSWER:
- 10. What animals had their tails cut off by the farmer's wife? ANSWER:







5 3 7 9 5 6 1 9 8 6 8 6 3 4 8 3 1 7 2 6 6 2 8 4 1 9 5 8 7 9 If you are more interested in mind games and thinking, you could have a go at playing games such as:

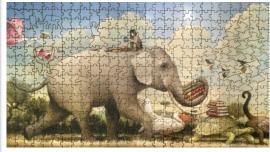
- Rummikub
- Scrabble
- Word searches
- Crossword puzzles
- Sudoku
- Dominos



How about having a go at jigsaw puzzle? One member personally finds those with 500 pieces to be what works best for them. But have a play around and find out what works best for you, whether that will be mean having fewer pieces or more

You can purchase them online or in store!

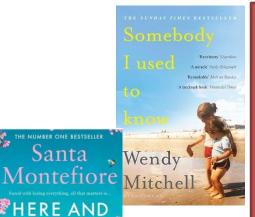








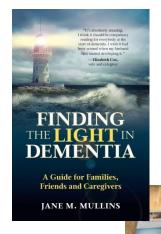
If you are more interested in reading, here are some books that some of our members recommended:





- Wendy Mitchell Somebody I used to know
- **Christine Bryden Dancing** with Dementia
- **Aster Five Minutes in the** Morning/Evening
- **Gill Hasson Mindfulness Pocketbook**
- Jane Mullins Finding the **Light in Dementia**
- Santa Montefiore Here and Now

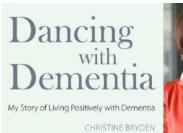
Our members found these books to be informative, interesting, hopeful and above all, real.







Santa







An alternative could be to read a book of short stories instead, like these:

- Adam Kay Quick Reads This Is Going to Hurt
- Claire Mackintosh The Donor: Quick Read
- Fanny Blake A Fresh Start (Quick Reads)

Or if you do not want to read, how using about an audio book, where you the books are read to you



One member found 'Dementia Diaries' to be useful and interesting

https://dementiadiaries.org/



If you prefer to be more hands on, here is some inspiration from our members as all these pictures are of things they have made themselves



These pictures have been taken by some of our members who have taken on their own projects. One person built their own bar and another person built a hedgehog house!





A lovely example of needle felting – she has been named Mavis!

Examples of crocheting – various blankets and some flower garlands







Rock painting

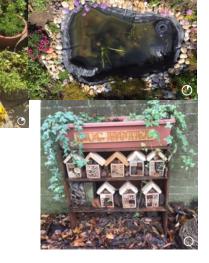


One of our late member's lovely

garden

One member's flower pots as well as the mini pond and bug hotel they created







Easter wreath

> One member learnt Macramé

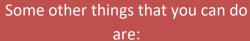




One member and her grandson won a prize in sunflower competition. Well done!







- Gardening
- Arts
 - Drawing/Painting
 - Sculpting
 - Jewellery making
- Crafts
 - Embroidery
 - Scrapbooking
 - Wood-carving
- DIY: make a...
 - o (Book)shelf
 - o Recycling bin
 - o Bird feeder
 - Flower arrangement









If textbooks and instructions are not enough help in carrying out your activity, members have found YouTube to be a very helpful place as it gives you a visual presentation of what you need to do and you can follow along at your own pace



Some members struggle to follow soaps/dramas as they keep adding too many new characters and complicating storylines. Another member suggested watching anthology series which are shows or film series that present a different story and a different set of characters in each episode, season or segment. Here are some examples:



Recommended shows/films

- Vera
- The Ripper
- The Pembrokeshire Murders
- Back to Life
- Bay
- Finding Alice
- Helicopter ER
- ER

Or how about re-watching old shows you used to enjoy!

You can watch these programmes on catch-up on sites such as ITV Hub, BBC iPlayer and Netflix





The power of music!





Music is a very powerful tool, whether this is listening to music, singing, playing an instrument or even dancing! It reinforces our sense of identity and helps us connect with people close to us. It can enable people to express themselves creatively beyond words as well as encourage physical exercise, dance or movement. A couple of our members are part of singing group which they love, they find that it makes them feel good and allows them to focus on their breathing too which is also beneficial. Another member has enjoyed taking up learning an acoustic guitar (shown on the right) since their diagnosis.





Some of our members are part of a singing group called YO songsters, hosted by Musical Walkabout which is run by Nina Clark in collaboration with Lisa Doherty from Dementia Support Services.

Here is a lovely picture of some of the members!



For those of you worried about child care responsibilities, one member shares their personal experience

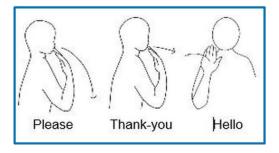
I can tell you that after my diagnosis I felt absolutely stunned. The thought of not knowing what I could and couldn't do. Now, with over two years from the diagnosis I still care for my grandson who is now three whilst his parents are at work. I don't have him every day as his father is a shift worker. My granddaughter, who is twelve needs transporting to / from school which means I am hands on quite a lot, especially with our grandson. Also, I have a 16 year old who has autism and she also needs to be taken / from school and appointments. I have developed a system to keep track of these, to deal and act upon their outcomes. As I cannot rely on my memory I have adapted how I record this information, I now have a book specifically recording everything I do for or am told regarding her is recorded in her "book". I can refer to the book to refresh my memory, that way I am still doing what I feel is my role as her mother. Having been in childcare and education for over thirty five years I didn't feel ready to sit and do nothing. I very much feel that looking after my grandchildren and daughter reaffirms that I still have a very important role in life and that I am helping my family whilst they are working. Above all, I enjoy what I am doing.

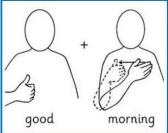


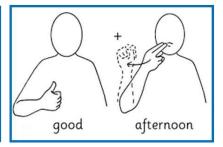


Makaton is a language programme that allows people to communicate by using symbols (pictures), signs (gestures) and speech. It can be used as the main method of communication or as a way to support your speech. This is something our SUNshiners are enthusiastic about and so they will be learning this together.

Here are a few basic signs:







You can find out more about Makaton by following this link:

https://www.makaton.org/

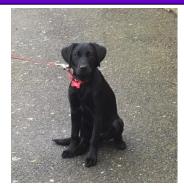
If you're an animal lover, you'll love this page as it's filled with our SUNshiner's pets!

Some of our members have found that having a pet has really helped them. They offer companionship if you are lonely, and can be stress busters if you are feeling low or want comfort, and some say they are even therapeutic. Looking after a pet can help give structure to your life as it gives you something to do and so can keep you active too. However, it is important to take into consideration that looking after a pet is not easy as you will have a lot of responsibilities. Bear in mind things like if you or others have allergies, the fact that you may have to house-train them and the cost of food, shelter and supplies.

If you wish to get a pet, make sure that you have the proper knowledge to keep them as best as possible.

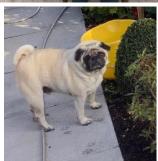












What our members have to say:

One member said: "My puppy Betsy (black Labrador) always cheers me up if I feel low. She makes me do things like walking her and caring for her needs."

Another member said: "These are two photos of my cats. The black and white one is Harley and the tortoiseshell is Rosa. I have always had cats since I was 23, and I can't envision my life without them. Especially now with my dementia. Harley doesn't mind when he gets fed but Rosa wakes me up by placing her paws on my eyelids gently, then my nose and if that doesn't work she sits on me which usually works because she is heavy. They make me laugh often!"

Our members would also like to share some tips they have found useful!

1. Have a list of things you need to do for the day/week. And make sure before you leave the house, to write a list of items you need get for when you go shopping as you may forget once you get there





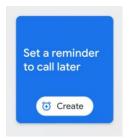
2. Use communal/shared calendars with friends and family so that everyone can keep on top of what events have been planned. And even if you forget, someone else can give you a reminder!





3. Use reminders on your device if you have them. They can be helpful in remembering things such as doctor appointments, hospital appointments and any other thing you can think of!





4. Make use of the 'Hidden disability' lanyards if you need them. A number of supermarkets stock these, including Marks and Spencer, Sainsbury's, Argos, Tesco, and Morrisons. Or you can purchase them on the Hidden Disability website: https://hiddendisabilitiesstore.com/







To conclude, our members have a message for you:

When you are first diagnosed, you may be processing and adjusting for the first 2 years or so but that does not mean your life ends there. Do not discard the hobbies that you used to like as your diagnosis does not mean you have to stop doing them. It could simply mean that you might need to simplify the activity or maybe you just need a bit of help/support. Your needs will be different to others and you just need to find out what works for you because you are your own person. You will have both good days and bad days so remember that it's okay not to be okay. It is important to express to others how you are feeling so they can understand and support you in the way you need. Make sure to always be kind to yourself and remember that you are not alone, you can always find help!

Some helpful links are below:

https://www.kmpt.nhs.uk/get-involved/service-user-and-carer/living-with-dementia/

https://www.kmpt.nhs.uk/get-involved/service-user-and-carer/living-with-dementia/sunshiners/

https://www.dementiavoices.org.uk/

https://www.dementiauk.org/

https://www.ageuk.org.uk/information-advice/health-wellbeing/conditions-illnesses/dementia/

https://www.alzheimersresearchuk.org/

https://www.alzheimers.org.uk/

https://www.alz.org/

https://www.raredementiasupport.org/

https://dementiadiaries.org/

https://dementiasupportservices.co.uk/

ANSWERS TO QUIZ:

Hercules
 Wild goat
 A duck
 Albatross
 Watership Down
 Moby Dick
 China

5. Golf 10. Three blind mice