

LIVING WELL WITH YOUNG ONSET DEMENTIA

These are some suggestions made by people we spoke to in our research study into experiences of young onset dementia (before the age of 65 years). You may like to try or adapt some of them to help you manage life with young onset dementia. As part of our study, people living with dementia and their family carers wanted to share these ideas in a leaflet.

Family members/carers:


- Get support from other people in your situation.
- Have a big diary for the person living with dementia to use.
- Allow yourself to take time out and pamper yourself.
Put yourself first, sometimes.
- Be aware that you cannot control the illness.
- You can't wrap them up in cotton wool so let the person living with dementia do what they want to do within reason.
- Listen to music or singing may help.
- You've got to look after yourself.
- Try a meditation and mindfulness course. Live in the moment.
- Accept when you do need help.
- Keep yourself in a routine with the person living with dementia.
- Get as much information as you can about what's out there that can help you.
- You have to remember to let things go and just let things be.
- Remember it's the illness talking when hurtful things are said.
- You don't have to be perfect all the time.
- Don't wait until breaking point.

- ✓ It's OK to get it wrong.
- ✓ Do stuff that the person living with dementia really enjoys.
- ✓ It helps if you can build up your confidence as a carer.

People living with dementia:

- ✓ Keep your keys in your shoe because as soon as you put your shoe on your keys are there.
- ✓ Keep things in the same place.
- ✓ Keep routines.
- ✓ Put labels on your cupboards so you know what's inside.
- ✓ Use a waterproof marker to write S and C on shampoo and conditioner bottles.
- ✓ Use a Dictaphone to record what you have to do the next day.
- ✓ Have a pot/glass with your toothpaste and toothbrush in.
- ✓ Use a big diary and visitors can record when they've been there, especially if carers have visited.
- ✓ Calendars with bigger boxes to write in.
- ✓ Use audiobooks instead of reading.
- ✓ A sign on the door reminding yourself to lock the door.
- ✓ Use a blister pack/tablet dispensing system.
- ✓ Use a watch that alarms you to take your medication.
- ✓ Have a tracking device so your carer knows where you are by using their phone.
- ✓ If you're having a bad day with 'brain fog', put the radio on or some music and just relax.
- ✓ Let the people you live with know you're having a bad day.
- ✓ Exercise even if just walking round the block.
- ✓ Get some social support and join a group.
- ✓ Remember what you CAN do.
- ✓ Structure your day.
- ✓ Talk to your peers.
- ✓ Take one day at a time.

See other resources at:

 hub.salford.ac.uk/salford-yod

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