



Wellbeing for Life

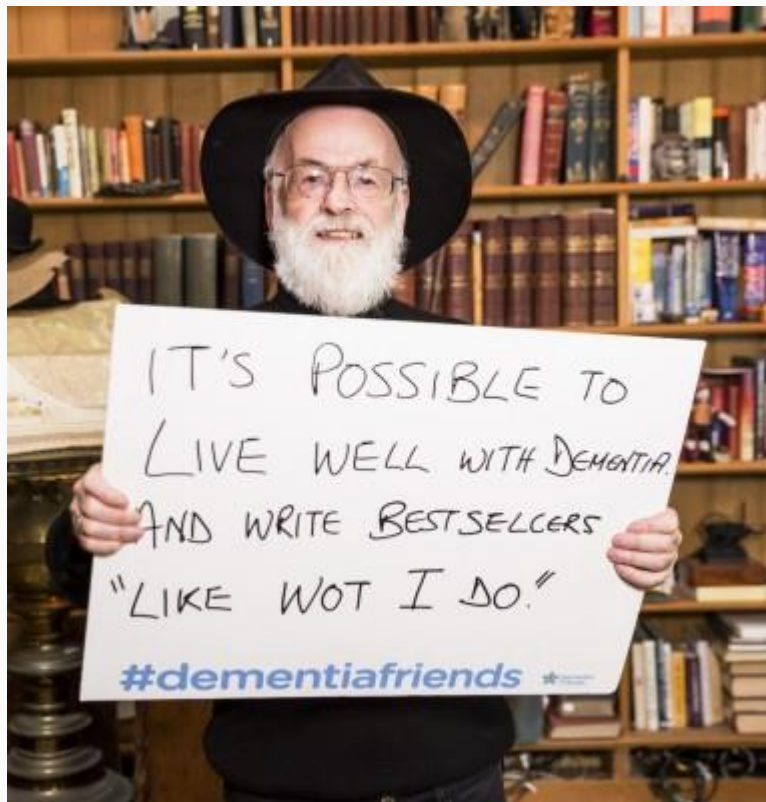
Living well with Dementia



Learning Outcomes

- To understand the term 'living well' with dementia.
- To appreciate the possibilities and difficulties associated with living well.
- To be knowledgeable about practical ways to support the person to live well.
- To be aware of your role in helping the person to live well.
- To be able to provide the "just right support" to enable the person to live well.

What is 'Living Well' with Dementia?



The phrase 'Living Well with Dementia' is one you may have heard before.

The idea behind it is the concept that a person with dementia can still live a positive and fulfilling life, enjoying hobbies and interests they pursued before their diagnosis, participating in new activities, and feeling a sense of achievement and wellbeing.

As Terry Pratchett said during his life with dementia:

"It's possible to live well with dementia and write bestsellers 'like wot I do' "



What is 'Living Well' with Dementia?

Living well with dementia is the opposite of the more traditional and stigmatised view that all people with dementia are “*sufferers*” who live negative lives with an incurable and degenerative condition.

This is a vision of a life with dementia that has been roundly rejected by people who live with dementia, the majority of whom are able to live well with dementia, or at least as well as possible and better than they otherwise might or that others may perceive is possible.

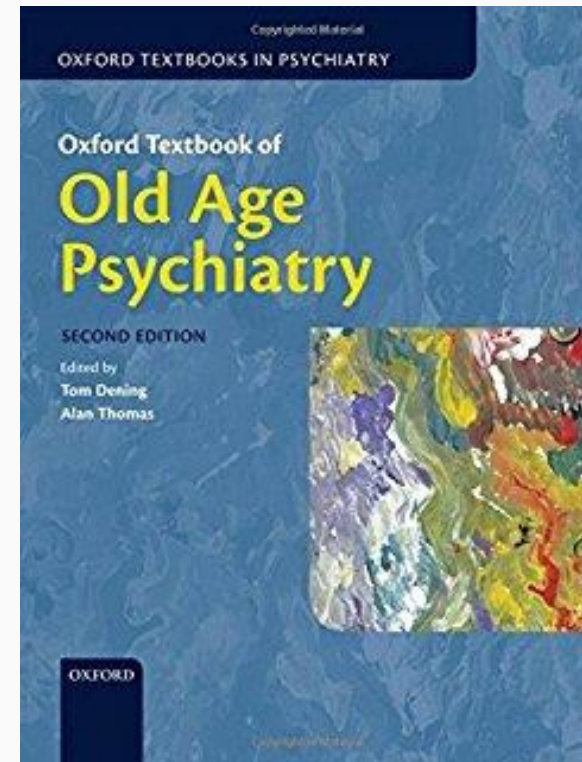
For more information, please see our Module on 'Challenging Discrimination and Stigma' in Theme 1 Fit for the Future.

Is Living Well Always Possible?

“Not every day is wonderful and there are certainly some difficult times – but we are going forward, taking risks and living life to the full. There is still confusion and the need to make adjustments, to be flexible and learn.”

Hello, I'm me! Living well with dementia,
Chapter 30, June and Brian Hennell, Oxford
University Press

A key feature of living with dementia, much like living for all of us, is good days and bad days. With this in mind, it's unlikely a person will always live well with dementia.





Is Living Well Always Possible?

When a person's symptoms become more severe, new symptoms appear, if they are unwell with another illness or condition, or a difficult or upsetting event occurs, the person is unlikely to be feeling very positive.

It is important to be realistic that there are going to be tough times for all involved - the person living with dementia, their family and friends and the people that care for them. But with the right support, you can enable the person to find a new sense of living well as their dementia changes and/or advances, or other life events impact on their ability to live well.

Capturing the good days can give people faith that they can still feel like the person they were before they were diagnosed with dementia.



What does Living Well Look Like in Practice?

Living well with dementia means following a healthy diet and lifestyle, having social interaction and mental stimulation, benefitting from healthy sleep patterns, receiving appropriate care and support (including pharmacological and non-pharmacological treatments for dementia), and feeling a sense of wellbeing. For more information, please see our Module on 'Wellbeing' in Theme 1 Fit for the Future.

A key part of living well is the support network around the person. Their family, peers, friends and staff all have an important contribution to make to help the person to live well with their dementia. The person's diagnosis doesn't just affect the person, but everyone who knows and loves them too.

Being mindful of this and making a combined effort to help the person to live well can be beneficial for everyone in coping with their feelings and emotions. For more information, please see our Module on 'Emotional Impact of Dementia' in Theme 5 The Dementia Pathway



What does Living Well Look Like in Practice?

Another key element of living well comes from the person's environment.

An environment that is dementia friendly (enabling and responsive to the person's needs) is vital to support the person's independence, orientation and ability to continue to live as they wish to. For more information, please see our Module on 'Dementia Friendly Environments' in Theme 5 The Dementia Pathway.

When living well is achieved, the person will feel valued, included, worthwhile, useful, needed and loved.





Healthy Diet and Lifestyle

Having a healthy diet and lifestyle is important for everyone, and is a key part of living well with dementia. Having a good attitude towards healthy eating and exercise not only helps improve health, it makes you feel better in everyday life.

Diet:

Be aware that changes in eating habits can occur as dementia progresses. This may be because the person struggles to find the right words to ask for food, or their taste buds change. Support is needed to ensure a healthy weight and good nutrition.

Make food interesting and varied so that it looks appetising and tastes good. Involve the person with preparing food, as involvement with preparation and smelling the food can increase appetite. Also remember, that a person's 'favourite' foods may change as their taste buds change. What was once their favourite meal may no longer be appetising to the person.

Ensure you continue to offer them a choice in their meals and look out for a change in preferences. For more information, please see our Module on 'Eating and Drinking' in Theme 1 Fit for the Future.

Healthy Diet and Lifestyle

Exercise:

If the person has a particular exercise routine, support them to continue with that. If the person is reluctant to take exercise, try to be innovative – walk to local shops or cafés rather than using transport. If the person is less mobile, consider seated exercises. And try to make exercise fun by incorporating music, making it a group activity and joining in yourself.

Smoking and Drinking:

Government advice is to stop smoking and only drink alcohol within recommended guidelines to ensure a person can live a life of optimal health, including when the person is living with dementia. The person's GP can offer advice and support about cutting down or stopping smoking and/or drinking alcohol.





Social Interaction and Mental Stimulation

Being socially active has huge benefits for physical and mental health and is a key part of living well with dementia. A diagnosis of dementia is life changing, making the person more at risk of isolation, loneliness and depression, so ensuring the person you support has social interaction and mental stimulation is of particular importance.

Plan activities and events - the results will be worth it. Take time to see what is happening in the local area, both dementia specific events (like Memory Cafés and Singing for the Brain) and general community events.

Make sure you involve the person living with dementia, helping them to take control of what they do and when. The person may find new interests and make new friends through trying things they have never considered before.



Social Interaction and Mental Stimulation

Mental stimulation includes trying new puzzles and problem-solving activities – there are many dementia-friendly examples available that are created specifically for a person with cognitive impairment.

Remember that not everything has to be big and bold. Concentrating on the small things, like talking about the plants and birds whilst out walking, can be reassuring and helpful if the person is having a bad day.

Finding ways to gently challenge the person, without making them feel out of their depth or a failure is important. You will need to know the person well in order to work out what is right for them and keep the resulting activities under constant review to see if they are still suitable for the person.



Healthy Sleep Patterns

Sleep patterns can change at any time and when a person is living with dementia, these changes can often be negative ones. A change of sleep pattern can have a significant effect on the person's wellbeing, leaving the person sleep deprived and constantly tired, which then has a negative effect on the person's day-to-day life, or result in the person sleeping in the day which can lead to them being up and active at night time.

Dementia can also disorientate the person, which might affect their sleep patterns if the person thinks it is morning and they should be getting washed and dressed when it is actually night time.

Physical changes in the person's brain might also lead to disturbances in the body clock that are sometimes described as '*sundowning*', which is when the person shows an increase in changed behaviours in the late afternoon or early evening.

Sleeping problems may be particularly acute when the clocks change or there are sudden changes in temperatures (going from cold weather to warm/hot weather and vice versa). For more information, please see our Module on 'Changed Behaviour' in Theme 5 The Dementia Pathway, and the booklet accompanying that module 'Wakefulness and Disturbed Sleeping'.

Healthy Sleep Patterns

When addressing sleeping problems with a person at night, make sure you have a calm approach and talk gently to reassure the person. If you work at night a good tip is to wear either pyjamas or a dressing gown so when the person sees you they are reminded it's night time.

Other tips include:

- Spending time doing a relaxing activity before bed
- Have a clock so the person can remind themselves what time it is – there are clocks specifically made to help people with dementia
- Install blackout blinds in the bedroom to minimise external light
- Reduce the intake of caffeine as this can keep a person awake

For more information, please see our Module on 'Dementia Friendly Environments' in Theme 5 The Dementia Pathway.





Care and Support

The person should have access to pharmacological and non-pharmacological treatments for dementia, have regular medication reviews, and consult their GP if anything significant changes with their health. For more information, please see our Module on 'Treatments' in Theme 5 The Dementia Pathway.

Alongside healthcare interventions, the person will need positive and enabling support. In the aftermath of their diagnosis and at any point thereafter, the person may benefit from the opportunity to access counselling or similar interventions (like talking therapies) designed to allow the person to express how they are feeling, particularly if they are worried, anxious or depressed.

Sometimes the chance to talk to someone not directly connected to their personal situation can help the person to fully express themselves and work on coping strategies.



Wellbeing

Wellbeing is another vital aspect of living well, both in the sense that the person feels that their wellbeing is currently positive, and that they have opportunities to enhance their wellbeing further.

In addition, be mindful of the wellbeing of everyone who forms part of the person's support network – if they are feeling a sense of wellbeing, they are more likely to be able to support the person's wellbeing.

For more information, please see our Module on 'Wellbeing' in Theme 1 Fit for the Future.



Nourishing the Person's Support Network

Creating a circle of support, comprised of people who are important to the person with dementia, is essential to help the person to live well.

A circle of support will help a person living with dementia cope with everyday challenges. Having people to turn to and offload thoughts and feelings to helps reduce fear and anxiety.

Ways to nourish the person's support network include:

- Encouraging the person to spend time with people they love. This naturally releases feel good endorphins that make the person relaxed and happy.
- Help the person connect with others - embrace time spent with family, friends and peers, go to the party or the lunch date, meet up with people the person has not seen in a while.



Social Interaction and Mental Stimulation

- Time away from everyday life usually always makes a person feel better. This is sometimes called “*recharging your batteries*” or “*a change of walls*”. Think about booking a day out, weekend away or even a holiday, including friends and peers if the person wants. Some holiday organisations specialise in dementia friendly accommodation or adventures.
- Investigate local peer support networks that may benefit the person – DEEP:
<http://dementiavoices.org.uk>

For more information, please see our Module on ‘Supporting Peers and Friends’ in Theme 5 The Dementia Pathway.



Your Role in Helping a Person to Live Well with Dementia

To support someone to live well with dementia you will provide good person centred support that focuses on:

- What is important to and for the person.
- Considers their needs, preferences and wishes.
- Uses their life story to provide meaningful support and interaction. For more information, please see our Module on 'Life Story' in Theme 2 Person Centred Approaches Involves all those who know and care for the person.



Social Interaction and Mental Stimulation

An important part of your role is how you communicate and interact with the person.

Keep the following tips in mind:

- Keep information simple and in a way that makes sense to the person, repeating frequently but in a calm and reassuring manner.
- Avoid telling the person you've told them something before, as this could confuse the person further and also make them feel inadequate that they couldn't remember this.
- Whenever you are having a conversation with the person, address them directly as this will help the person to focus.
- When asking questions give cues rather than using vague questioning. For example: "Did you have dinner?" Instead of "Have you had dinner?"

Skills Staff Need

Your belief in the person's ability to live well, and your skills in helping to support the person with that aspiration are of vital importance.

These skills include:

- **Patience and empathy:** A person with dementia will need more time to think and to act, so don't rush them.
- **Observation:** If you can see that the person is having a bad day and requires more time or explanation of what's happening, then it's your role to reassure the person.
- **Positive approach:** Always approach the person with a smile and be aware that they may be reading your body language and if this isn't right it will create a negative impression. It is your responsibility to be mindful of how you appear to the person.

Skills Staff Need

- **Reassurance:** Reassure the person if they can't remember your name – don't test them by asking them to tell you your name. Instead, make it part every interaction to introduce yourself with your name, how they know you or your role, and what you are doing.

hello my name is... <https://hellomynameis.org.uk/>

- **Adaptability:** It is important to be adaptable and change things to suit the person's skills and abilities as they are now. This will encourage independence and keep the person active and their mind busy for longer – improving their quality of life and providing a sense of wellbeing.



Providing the “Just Right Support”

Ultimately, when you support a person with dementia, your role is to provide the “*just right support*”.

Doing this includes:

- Keeping the person at the centre of their support. Always involve them in decisions. When you support a person always check you are involving them as much as possible and in a way that makes sense to them. You may have to adjust parts of your support or break the activity into small steps to ensure the person is as involved as possible. For more information, please see our Module on ‘Person Centred Care and Support’ in Theme 2 Person Centred Approaches.

Providing the “Just Right Support”

- Supporting the person’s independence. They need “just right support” to enable them to do things for themselves. They may require a little more help to do something, or to be shown a new way of doing something. You will need to be creative in your approach. For more information, please see our Module on ‘Promoting Independence and Safety’ in Theme 4 Good Support.





Providing the “Just Right Support”

- Keeping in mind, “What if this was me?” Imagine how you would feel if a person came into your home and just started doing things without asking you. This would be frustrating and make you feel worthless, the exact opposite of the feelings associated with living well.
- Knowing the person’s routine and supporting them to maintain it, or change it if needed, to ensure their day makes sense to them.
- Responding to the person’s needs in a timely way will help reduce negative feelings and provide a sense of respect and comfort.
- As their dementia progresses, they may forget some of their daily routines and activities. For example, they may forget that they have been moved using a hoist before, even if this is something you do daily and have done daily for years. Be mindful to always explain what you are about to do, and how you are about to move or lift the person – and provide clear instructions of what you are doing and why. Again, reassurance is key.



Ten Top Tips to Support a Person To Live Well with Dementia

- 1) Encourage a healthy, balanced diet
- 2) Keep physically active
- 3) Reduce or stop alcohol consumption
- 4) Reduce or stop smoking
- 5) Keep connected with others – support existing relationships as well as new ones
- 6) Keep the brain active
- 7) Encourage good sleep habits
- 8) Be aware of any unmet health needs – contact the person’s GP if you have concerns
- 9) Champion the person’s needs, preferences and wishes
- 10) Provide the “just right” amount of support



Notes:



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