



More than Memory: *Understanding and Supporting Mental Wellbeing in those with Dementia and their Carers*



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St Andrews

An interactive and brief guide to fostering better mental wellbeing in people with mild to moderate dementia and their carers.
Designed for people with dementia and their non-professional and professional caregivers.

Use these questions to direct you to the appropriate part of this guide:

Do you have dementia?

YES Section 1 contains information on ways you can look after and improve your own mental wellbeing.

Do you care for a friend or family member with dementia?

YES Section 2 contains information on ways you can support your own mental wellbeing and the wellbeing of your friend or family member

Do you care for people with dementia and/or their carers professionally?

YES Section 3 contains information on how you can support those you care for with a dementia diagnosis and interventions to support carers' mental wellbeing.

SECTION 1:

I feel my mental wellbeing has suffered following my dementia diagnosis, is this normal?

YES. When you have a diagnosis of dementia, it's **very common** to experience periods of poor mental wellbeing – it is estimated that **up to 75%** of people with dementia experience this¹ and, so, if you feel as if your mental health is suffering, you are absolutely **not alone**.

Most commonly, you may experience depression, apathy and agitation in particular².

- **Depression** causes a low mood of dissatisfaction alongside a loss of interest and/or pleasure.³
- **Apathy** means you suffer from reduced motivation⁴
- **Anxiety** may mean you suffer from excessive worry that is difficult to control, restlessness, irritability, muscle tension or respiratory difficulties.⁵
- Suffering from **agitation** means you may feel an inner tension which makes it hard to sit still.⁶



These, anxiety,⁷ and other symptoms including **disturbances to sleeping and eating** have been observed in a significant proportion of people with dementia.⁸ Therefore, if you feel you are suffering from any of the above, you may need to make some changes to support your mental health.

My wellbeing checklist:

- I understand it is very common to experience depression, apathy, anxiety and agitation
- I understand I may experience disturbances in my sleeping and eating habits
- The next section of this guide will give me tools on how to improve my mental wellbeing

This guide will give you some ways you can help improve your own mental wellbeing based on evidence from scientific studies conducted on others who also have dementia.

However, **REMEMBER**, that you can always visit your GP with any concerns if you find making behavioural changes doesn't help.

SECTION 1:

What changes can I make to improve my own mental wellbeing?

Scientific evidence examining people with dementia has shown that there are several things you can do to improve your own sense of wellbeing. These include:

Spending time **outdoors**

Spend time with others in **groups**

If you can, spend time **exercising**

Adapted from ^{a, b, c}

While you may be anxious to go outside or meet people, evidence shows that these activities can help improve wellbeing.^{a, b, c} If you feel like **you would benefit** from meeting with a group of other people with dementia, there are multiple groups all around the country. The video below (**Fig. 1**) gives a brief introduction to some of the groups in the UK and an idea of the work they're doing for and with people with dementia.

Some groups provide activities such as dementia cafés, where you can socialise with other people with dementia, and others run **walking groups** so you can spend time outdoors, exercising, and with others – all in one go! In the video, you'll see that the members of these groups report an increase in confidence, companionship – and that it “gets the brain cells going!”

You can access information about **local dementia services** in Scotland by clicking [here](#).

My wellbeing checklist:

- By spending time outdoors, meeting people in a group, and spending time exercising, I may improve my mental wellbeing
- There are groups I can attend which might help in my local area
- I can also talk to my GP about my mental wellbeing if I feel it continues to be problematic



Fig. 1: This video from the [Mental Health Foundation](#) shows the variety of groups in the UK working to bring people with dementia together in order to educate people, campaign, and provide a service. The largest campaign-based group in Scotland is the [Scottish Dementia Working Group](#).

It is also available here: <https://youtu.be/mdqucRPRQTo>

SECTION 2: How can I help support my own wellbeing and the wellbeing of the person I care for?

Almost
25% of
carers experience
clinical-level
anxiety.^e

Looking after yourself is **part** of looking after the person you care for!

If since undertaking your caring role you have found that your wellbeing has suffered as a result – **you are not alone**. A review into the wellbeing of carers found a reduction in subjective wellbeing and mental health of those who care for people with dementia and an increase of burden and feelings of anguish.⁹ Depression and anxiety in particular affect the carer population.¹⁰

However, it should be noted that there are ways that you can help to support your own mental wellbeing – which is very important. Work examining carers has shown there is a direct influence of your ability to cope on outcomes for the care-recipient¹¹ – and so by looking after yourself, you help look after them!

Attending a **support group** gives you the chance to express your emotions in a safe environment, increases your social network and thus helps to overcome feelings of isolation¹² – which can help improve wellbeing in carers.¹³ Social networks are important in your ability to cope¹⁴ – so make sure to reach out to family or friends if you need help.

Using services which provide **respite care** – to allow you to have time for yourself – have also been scientifically shown to improve caregiver wellbeing.¹⁵ Information from the NHS on how you can organise respite care be found by clicking [here](#). You can see these ideas discussed by other carers in the the video below (**Fig. 2**).

My wellbeing checklist:

- I understand that poor mental wellbeing is common in carers of people with dementia
- I understand that my mental wellbeing is important and should be considered a **part** of my carer role, not an extra requirement
- I understand that taking time for myself and my own activities (such as going to dementia carer groups) can help to improve my wellbeing
- I understand that I can contact my GP for support to manage my own mental health needs if they persist.

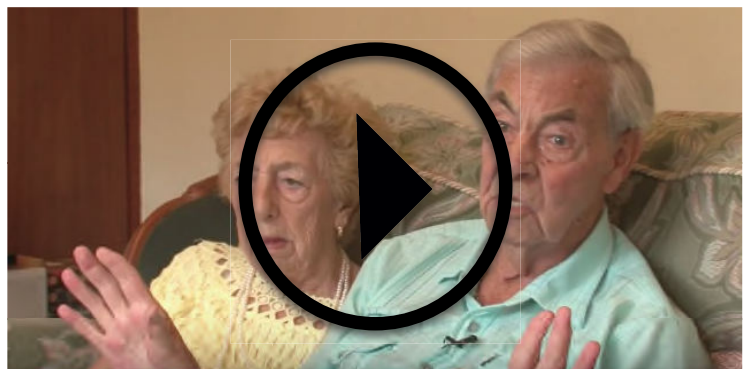


Fig. 2: This 20 minute video discusses the challenges for carers of people with dementia and how they can attempt to support their own mental wellbeing. It is also available here: <https://youtu.be/bleFH89GD9k>

SECTION 2:

The person I am caring for seems depressed/ anxious/is irritable. Is this normal? What can I do to help?

It is estimated that **up to 75%** of people with dementia experience poor mental wellbeing¹⁶ and, so, it is very common for this to be the case.

Most commonly, you may observe the person you are caring for is depressed, apathetic or agitated¹⁷. Anxiety¹⁸ and other symptoms including disturbances to both sleeping and eating patterns are also very common.¹⁹

There are a few simple things you can encourage the person you care for to do which will help to improve their mental wellbeing.

Engaging in **exercise**²⁰, spending time **outdoors**²¹ (even just in a garden²²) and participating in **group** activities²³ (e.g. your local dementia group – which can be found [here](#)) have all been shown to help.

Encouraging the person you care for to attend a group may also offer you some free time – which will help your wellbeing too!



How you act towards the person you're caring for can have an impact on their wellbeing.

These principles (put forward by *Kitwood*) may seem obvious – but are worth bearing in mind when stressed.

- Try to avoid lying to get the person you care for to comply with your wishes
- Don't do something for them that they can do themselves – even if it takes them a while
- Try to avoid blaming them for the behaviour they exhibit – particularly if they are distressed
- Don't be inadvertently threatening
- Don't treat them as an outcast
- Don't give them information at a rate at which they can't keep up
- Don't ignore their mood states – in particular when they are distressed
- Don't exclude them from social environments
- Always remember to treat them as a human being – not an object which requires "servicing".

Adapted from Kitwood (1990).^d

Wellbeing checklist:

- I understand that poor mental wellbeing is common in people with dementia
- I understand that the actions I take can have an impact on the wellbeing of the person I care for (the Kitwood principles).
- I understand there are actions I can take to improve the mental wellbeing of the person I care for – such as encouraging outdoor activity, group participation and exercise where possible.

SECTION 3: How can I help support mental wellbeing in people with dementia?



As you will know, poor mental wellbeing is common in people who have dementia.¹⁶ Most commonly, you may observe symptoms of depression²⁴, apathy²⁵, agitation²⁶ or anxiety.²⁷ You may also have reports of disturbances to sleeping and eating.²⁸ See **Fig. 3** for a video briefly discussing these issues.

Care Home or Respite Facility

If you work in these settings here are a few things to bear in mind:

- People with dementia find activities which meet their psychological and social needs best to be most meaningful.^f
- **Avoid unstructured time** – engaging people with dementia in **group activities** improves wellbeing. In particular, **reminiscence-type activities** (such as handling old photographs or playing music) are most effective and *group craft activities* can also be effective.^c
- If you have access to a **therapeutic garden** or **safe outdoor space**, people with dementia benefit from time spent outdoors.^a

It's important that professional carers are aware of the **Kitwood principles** – social environment can influence wellbeing in dementia and carers inform this. See the **blue box** on p.6.

For more information on care practice in homes, a guide from the Alzheimer's Association can be found **here**.



Fig. 3 In this short video, Dr. Trisha Macnair, a speciality doctor in Medicine for the Elderly, talks about why anxiety and agitation may appear and what can be done to help. Also available here: <https://youtu.be/bM68lzugGc8>

SECTION 3:

Supporting the mental wellbeing of the carers of people with dementia



The mental wellbeing of non-professional carers is of the **utmost importance** to those in a professional care setting – this is because the carer’s capability of appropriately handling their care situation can be associated with both the time it takes for a patient to remain outside of a formal care setting²⁹ and **patient’s survival**³⁰.

A very detailed review³¹ has highlighted the increases of burden, **anguish** and reduction in subjective wellbeing and mental health of those who care for people with dementia. This review has gone on to recommend certain interventions from professional carers to help support non-professional carers’ coping capabilities. It is particularly important to give carers information since most carers wish to receive it – in both spoken and written forms – from professional caregivers.³² The key needs and aims emerging from the review³³ that must be observed in caregivers can be remembered by **DREAMIRS**:

DEPRESSION

RESPITE

EDUCATION

ANXIETY

MEDICAL NEEDS

ISOLATION

REDUCING BURDEN

SLEEP

INTERVENTIONS that a professional caregiver can take on behalf of the non-professional caregiver to improve their mental wellbeing:

- Increased **EDUCATION** and training given from professional caregiver to non-professional caregivers can help to ensure behaviours from people with dementia are better understood – and enhance understanding that behavioural problems can be part of the disease.
- Professional caregivers can help to help organise **RESPITE** care for the person with dementia to **REDUCE BURDEN** of the non-professional caregiver.
- **DEPRESSION** and **ANXIETY** should be treated using psychotherapy, psychoeducation and respite services – and professional caregivers may be able to provide a list of ways to access these service.
- **MEDICAL NEEDS** and **SLEEP** should be addressed by referring the carer to their own GP to enhance wellbeing.
- **ISOLATION** can be tackled using support groups, respite care to allow “own time”, therapy to increase social skills, or psychoeducation to allow the carer to appreciate the importance of support should they be reluctant to accept it.

All adapted from Sørensen et al.²⁶

Works consulted

Media used:

Title page: Photograph of mother and daughter available here, accessed November 20th, 2015 from:

<<https://pixabay.com/en/family-mother-daughter-women-515530/>>

Title page: Photograph of the University of St Andrews' Logo only available to those with a University of St Andrews' Login from the University of St Andrews' website, accessed November 20th, 2015 from:

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Page 2: no media used.

Page 4: "People with Dementia Speak Out!," YouTube video, 7:41, posted by "ukmentalhealth," 23 Oct, 2012, <<https://youtu.be/mdqucRPRQTo>>.

Page 5: "Care For The Carer", YouTube video, 20:23, posted by "fffilmsltd", 10 Oct, 2015, <<https://youtu.be/bleFH89GD9k>>

Page 6: Photograph of older lady available here, accessed November 20th, 2015 from:

<<https://pixabay.com/en/sad-woman-expression-stress-900363/>>

Page 7: Photograph of older lady and carer out walking, accessed November 20th, 2015 from:

<<https://pixabay.com/en/dependent-dementia-woman-old-age-441408/>>

Page 7: "What can be done to help agitation and anxiety in a dementia patient? - Trisha McNair." YouTube video, 2:15, posted by "BrainHub," 13 Mar, 2013, <<https://youtu.be/bM68lzugGc8>>

Page 8: Photograph of older couple available here, accessed November 20th, 2015 from:

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