



My Choice: An evidence-based resource to help People Live well with Dementia

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Introduction

The living well with dementia implementation lead, with support from other applied research collaboration colleagues, experts from further afield, our regional health and care system and people living with dementia has developed an accessible information resource to give people the information they need to help them live well with dementia.

This was developed because we consistently hear from system partners and people with lived experience that:

- There is little time to discuss the impact of a dementia diagnosis, or how to live well with dementia at a memory assessment
- Support and advice after a dementia diagnosis is inconsistent and far too often limited/absent
- This can lead to people living with dementia not having the information they need to live well, or knowing where to find trusted information. Having this information and therefore being able to make choices is an essential part of being enabled to self-manage their condition in a way that is relevant to them, improve their and their loved ones experiences and outcomes, and reduce avoidable demand on the rest of the health and care system.

“We went home with a diagnosis of dementia, and a carrier bag full of information, which was overwhelming and mostly not relevant to us at that stage. Then when we needed information, we struggled to find it” (Service User)

The aim of My Choice is to provide an evidence based, trusted, accessible, and useable resource, with links to trusted websites (e.g. the Alzheimer's Society) for additional information. It also includes information on other areas affecting people living with dementia such as accessing benefits and getting additional support as care needs change.





This includes:

- Eating well (including food supplements, hydration and alcohol).
- Heart health
- Hearing and vision
- Mental Health
- Sleep
- Physical activity
- Social activity
- Cognitive activity
- Helpful Habits
- Supportive Technology
- Planning for the future
- Other helpful information (e.g. benefits, accessing additional support)

The team undertook literature reviews on each topic, and summarised the key evidence for a lay audience with cognitive impairment.

To provide evidence-based information in an accessible way we adapted an approach developed by colleagues at the University of Sussex and Sussex Partnership Foundation Trust to provide information to people living with psychosis. This included using a thumbs sign to indicate the level of evidence behind an intervention.

Subject matter experts were then asked to review the literature review and the summary for accuracy.

The green thumbs up sign means there is a good level of evidence that a treatment, intervention or activity works to support health and wellbeing in dementia.	
The yellow sideways thumb means there is currently not enough evidence to know if the treatment, intervention or activity works to support health and wellbeing in dementia.	
The red downward thumb sign means there is enough evidence to suggest that the treatment, intervention or activity doesn't work to support health and wellbeing in dementia.	
The blue star means the interventions and activities can help protect people against dementia as they age, and are also helpful for people with mild cognitive impairment.	



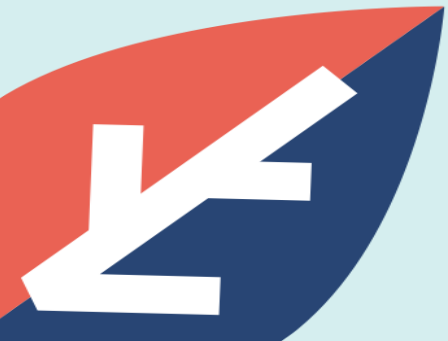
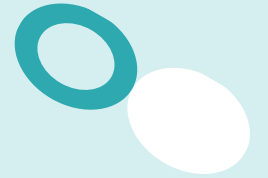
Through co design we identified areas of importance to PLWD that researchers and workforce had not initially thought of including:

- hearing and vision
- how to access more support for care when that is needed

We reduced a lot of detail to ensure the information was accessible to the widest population possible, while recognising people like different levels of information. For optimal accessibility we used plain language wherever possible, and incorporated dementia friendly design.

For some people my choice was too long, for others it did not contain enough detail- however the links to additional information were helpful for people wanting more information.

Our final step was to ask dementia support workers, and people living with dementia and their carers to review the booklet.



Responses from 7 dementia support workers

	Agree	Neither agree or disagree	Disagree
The information was relevant	100%	-	-
The information was easy to understand	72%	28%	-
The information was helpful	100%	-	-
I have read the whole of 'my choice'	72%	28%	-
I learnt something new	72%	28%	-
I intend to apply some of the recommendations in my work	100%	-	-
I have already used some of the recommendations in my work	100%	-	-
'My choice' will support personalised care planning	43%	57%	-
'My choice' will support discussions about planning for the future	86%	14%	-
I will go back to 'my choice' again for information in the future	72%	28%	-
I would share 'my choice' with my clients and their carers	86%	14%	-

Workforce key comments:

“a great tool”, “wonderful booklet”

“most people want to know so they can prepare”

“it will enable independence... and empower”

“good reminder of obvious prompts like keeping glasses clean”

“the booklet doesn’t try to do too much”

“very informative but may be too much”, “it is a lot of information to be taken in and may cause stress”

“would it be helpful to add things like teeth and swallowing difficulties in eating well?”

“I will go back to it for ideas and to refresh my memory”



Design feedback:

Check for dementia friendly design, colours, font size, spacing and more imagery

Liked the thumb symbols

Summary of the workforce feedback:

Overall, my choice received very positive feedback. Feedback demonstrated the tension between too much and too little information and detail, which can be personal preference.

All of the dementia support workforce feeding back felt 'my choice' was relevant and helpful and said they would apply the recommendations.

Two dementia support workers were unsure about how easy the booklet was to understand.

Five dementia support workers said they learnt something new.

It was not felt 'my choice' would help with developing care plans, but it was felt it would help with discussions about planning for the future. This is important because planning for the future and making wishes and preferences known while people are able to do so is very important when people are likely to lose their capacity to make those decisions in the future.

Overall the feedback from dementia support workers suggests that the my choice booklet is a useful, accessible resource, that will provide information in an accessible way to those people who want it, and could support independence, empower and help people plan for the future.

PLWD responses

12 PLWD, or carers on their behalf feedback on my choice.

Age range (68-92 m= 79y); years since diagnosis (10 yrs to 1month, m= 2 years); 8 male, 4 female; all English first language; 6 Alzheimer's Disease, 2 mixed, 2 vascular dementia, 1 'early dementia', 1 'dementia'.



	Agree	Neither agree or disagree	Disagree
The information was relevant to me	100%/12	-	-
The information was easy to understand	100%/12	-	-
The information was helpful	100%/12	-	-
I have read the whole of 'My choice'	75%/9	17%/2	-
I learnt something new	83%/10	8%/1	8%/1
I intend to adopt some of the recommendations in 'My choice'	83%/10	17%/2	-
I have already adopted some of the recommendations in My choice'	67%/8	25%/3	* 1 NA
I will go back to 'My choice' again for information in the future	75%/9	25%/3	-
I have shared 'My choice' with my care partner	83%/10	-	*2 NA
My care partner finds 'My choice' useful	83%/10		*2 NA

PLWD and carer key comments:

“Very informative but too much detail... people may be put off by that...overall though very useful to a person with a recent diagnosis”

“it would have been an invaluable step-by-step guide back at the beginning. It is clearly set out with a lot of really helpful information that we had to find for ourselves (rather a protracted and difficult process)”

“All in all a great document that should be given to people at diagnosis by their consultant”

“Particularly liked that is not asking the impossible”

“I don’t have a dementia support worker” “Dementia support worker NO EXISTENCE”

“It is impossible to contact or see my GP”, “with no support from my local GP, and no family close by people on their own face a very scary journey” These comments were made by 2 people living alone with dementia.

“easy to read... and in sections so it's easy to go back to... NICE recommendations gave it gravitas”

“Quality of evidence not clear... has Mediterranean diet got good evidence or is it trendy?”

“Not all carers can get benefits even if caring for someone 24 hours a day”

Summary of the people with lived experience feedback:

Overall, my choice received very positive feedback. All PLWD responses said the information was relevant, easy to understand and helpful.

Most people (>80%) learnt something new and intended to adopt some of the recommendations.

Feedback continued to demonstrate the tension between too much and too little information and detail preferences. Overall felt this was useful and most helpful if shared at diagnosis.

The PLWD feedback highlighted the inconsistency in dementia support post diagnosis and the additional challenge for people living alone and accessing GPs.

Overall summary

Both workforce (72-100%) and people living with dementia and their carers (100%) found the 'my choice booklet' relevant, easy to understand and helpful. In addition, the majority of reviewers (>72%) learnt something new and intended to adopt some of its evidence-based recommendations.

Recognition this information is otherwise not easily available, so there is a need for this type of resource. While there remains tension between too much or too little information/detail, overall it seems 'my choice' has achieved a reasonable balance for most.

There appears to be general consensus 'my choice' would be best given to people at, or shortly after their dementia diagnosis.

While people have said they said intend to adopt the findings further evaluation will be needed to assess wider impact, including on helping people towards planning for the future.

My choice has now been released and is available here: [file \(nih.ac.uk\)](file (nih.ac.uk))

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