



Welcome to Individuali-tea

Could a young onset specific
'toolkit' help individuals/families
with young onset dementia
to get tailored, helpful support?



youngdementianetwork.org/our-webinars

Individuali-tea

Evidence to support the need for improvement

Official guidance on care planning

An example of a tailored care plan that works

Enablers and blocks to good care planning

Ideas for evidence-based support interventions

What is the issue?

- People diagnosed with young onset dementia face a complex set of issues **BUT** all too often people are left to find out for themselves how to address them
- The best services are received from specialist young onset dementia teams **BUT** only 20% people with young onset dementia are in touch with a specialist team
- Therefore how can we improve the support people with young onset dementia get from all age dementia services?

Could a toolkit help?



- Videos focused on eight key needs
- A conversation guide/care planning document to identify support needed
- A resource pack on ways of meeting support needs
- A workshop about young onset dementia and using the toolkit

The Angela Project: Improving diagnosis and post-diagnostic support for young onset dementia



The Angela Project evidence provides the springboard for development of a toolkit



Good practice in young onset dementia

Improving diagnosis and support for younger people with dementia
Results from The Angela Project
A study on young onset dementia



Post-diagnostic support for people affected by young onset dementia is lacking

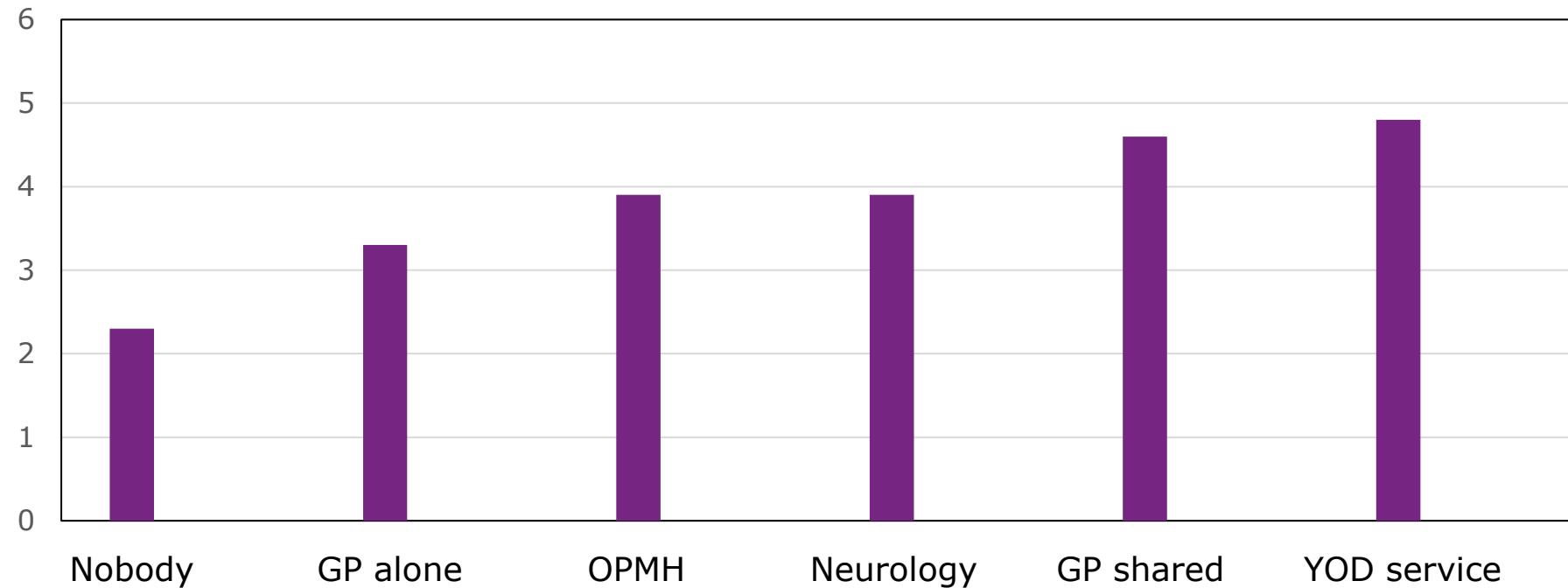
- 39% had seen no health professional in the previous three months
- 42% of those surveyed received no follow-up in the first six weeks after diagnosis
- 60% of those diagnosed in neurology services received no follow-up in the first six weeks
- 16% had no one managing their ongoing care
- Only 20% had ongoing management from young onset dementia specialists
- Although 57% of family carers provided support for five hours or more every day, 69% of carers reported there was no service that provided care for their relative to allow them to take a break
- In the last three months alone, most families spent the equivalent of £8,372 providing family care, whereas health and social care expenditure was only £394 for the same period



Quality indicators

Who manages care?	Nobody	GP	GP/shared care	Neurology	Older People's Mental Health	Specialist YOD service
Know who to contact if have questions	42%	54%	70%	80%	71%	98%
See same professional each time?	6%	37%	41%	14%	30%	47%
Have a key worker?	14%	17%	53%	13%	41%	76%

Satisfaction scores (0-6) by service managing care



Highly significant difference KW p< 0.0005

What explains higher satisfaction?

- Multiple regressions - 30.2% variance in satisfaction explained

Significantly higher when:

- Have ongoing care management from a specialist young onset dementia service
- Know who to contact
- Significantly lower when the GP alone or no one managed their care



Eight key needs

People with young onset dementia

- As independent as possible
- Active and engaged
- Physically/mentally as well as possible

Both

- Family relationships
- Social connections
- To contribute

Family supporters

- To know how to care
- To retain life beyond caring

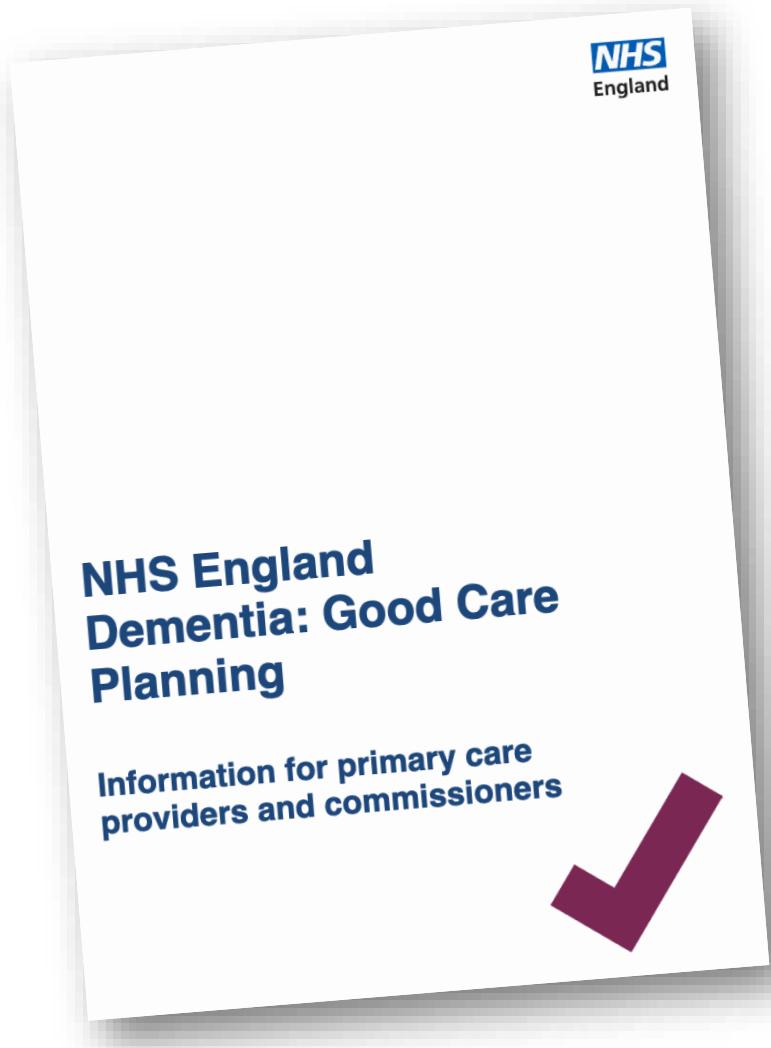
Services experienced as positive



Meet the eight needs by:

- Giving specialist advice and information
- Enabling financial security/stability
- Providing interventions for mental and physical health
- Providing support interventions for families
- Enabling independence while managing risk
- Giving access to age appropriate services
- Giving opportunities for social participation
- Giving opportunities to have a voice

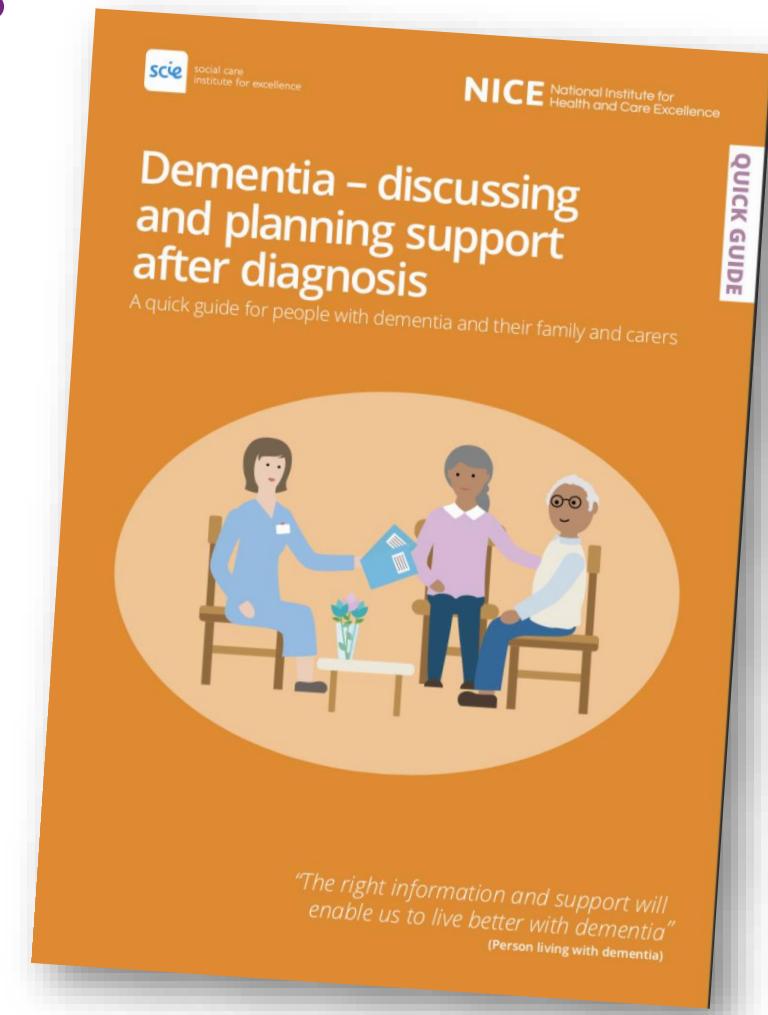
Guidance on care planning (updated 2020)



- Diagnosis review
- Effective support for carers
- Medication review
- Evaluate risk
- New symptoms inquiry
- Treatments and support
- Individuality
- Advance Care Planning

Dementia: assessment, management and support for people living with dementia and their carers

NICE guideline [NG97]
Published 20th June 2018





Care Plan

Care Plan - page 1



our Care Plan

Patient / Service User:		Keith Oliver		Care coordinator / Consultant:		GP:	Review Date:	20 Jul 2021
Activity	Delivery (How)	Location (Where)	Purpose (Why)	Professional (Who)	Interval (When)	Impact (Outcome)	Timeframe and review (start and finish date)	
Outpatient review	One to one with Rosemary for part of the appointment	Lifesize video call or face to face as needed	Monitoring		Every 4 months	Being cared for, monitored, check of my health, source of person centred clinical specialist advice	Indefinite	
Forget-me-nots / Envoy / Ambassador	Meetings, conferences, reading, advising, consulting with support of Rosemary and students	Video call (Zoom, Lifesize, Microsoft Teams) Canterbury London	Maintain self esteem, self worth and sense of value through contribution		Monthly and as required	On me On the work Connectedness <u>Support to manage demands and debriefing and processing.</u>	6 monthly review with	

Care Plan - page 2

our Care Plan

Patient / Service User: Keith Oliver

Care coordinator / Consultant:

GP:

Review Date:

Activity	Delivery (How)	Location (Where)	Purpose (Why)	Professional (Who)	Interval (When)	Impact (Outcome)	Timeframe and review (start and finish date)
Medication	Galantamine MR 24mg and Memantine 10mg once daily		Reduce symptoms of Alzheimer's disease		Collect every two months	Maintain function without adverse side effects	Indefinite
Inter-generational support from psychology students, volunteers	Formal and informal meetings	Canterbury and events as needed	Support with project work and travel, positive conversations, connecting with former roles	Pool of students /volunteers with supervisors	Once or twice per month	On me – helping young people, enrich their placement, offer guidance, experience, friendship On them – being a recipient of the above, encouragement, interest	Annual review
Primary care dementia review	One to one	Remote consultation or GP surgery	Check BP and needs		Annually (February)	Maintain physical health and stable blood pressure	Indefininte

Care Plan - page 3

our Care Plan

Patient / Service User: Keith Oliver

Care coordinator / Consultant:

GP:

Review Date:

Activity	Delivery (How)	Location (Where)	Purpose (Why)	Professional (Who)	Interval (When)	Impact (Outcome)	Timeframe and review (start and finish date)
Body Well	One to one	Blean	Spinal treatment and muscular and joint massage	Weekly spinal adjustment; Fortnightly deep tissue massage	Holistic lifestyle; sharing experience with Rosemary	Planned break for 2 months to evaluate	
Support from key friends	One to one		Emotional support to and from key friends		Manage difficult emotions	Indefinite	
Social walking	One to one with PPE / distancing	Familiar local routes	Physical and mental exercise	Three weekly		Review June 2021	
Talking therapy	2 x 30 mins per week – Tree of life focus	Virtual by Messenger video call / in person	Regular forum to share concerns and develop strategies	Every 2-3 weeks	Coping strategies to deal with anxiety	Ongoing with review as needed	

Care Plan - page 4

Other activities undertaken by the service user to live well with dementia – to be complete by service user

e.g. with family, friends, special groups, spiritual, exercise, interests, etc.

Crisis / urgent response plan If you need to reach out and ask for help between appointments, you may want to take up the following options:

- 1) **Between 8.30am and 5pm Monday – Friday** - contact xx xx on xxxxx xxxxxx – if no one is available to answer the phone straight away then please leave a message and this will be picked up within a short period of time and responded to. This may lead to you being transferred for a discussion with the duty clinician (a nurse or occupational therapist). If needed, they can see you that day or may suggest an alternative response. This could include a telephone call from xx at a given time, and/ or by an earlier appointment or home visit. Alternatively a call can be requested from xx.
- 2) **Out of hours** call KMPT Single Point of Access number on xxxxx – calls are handled by clinical staff and they can listen and discuss issues and arrange next working day response from Canterbury CMHTOP / Gregory House team.

Care plans for people with young onset dementia

Reinhard Guss, Clinical Psychologist

NHS Personalised Care Plan
Giving patients control of their own health

Patient Details

Name: JONES, Adam (Mr)	Date of Birth: 08-Apr-1967
Address: 3 MILL Road, Upper Moor Side, Booth Wood, West Yorkshire, WF8	NHS Number: 560 575 3588
Home Tel: 06453150074	Mobile Tel:
Residential status: No events found.	Main language: unknown
Home access information: No events found.	Door access keycode: No events found.

GP Practice Details

Usual GP: BURNS, Robert (Dr)
Practice name: Ardens Training (Practice 2)
Practice address: Fulford Grange, Mickiefield Lane, Rawdon, Leeds, Yorkshire, LS19 6BA
Practice telephone: 01133800000
Case Manager (if applicable): No events found.
Care Co-ordinator: No events found.

Other people involved in care

Other professionals:	No events found.
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Patient Carers

No events found.
Patient Carers
No patient carers recorded.

I aim to provide your child with the best possible care, meet their individual needs, and support them with their learning and development. Please can you assist me in completing this Personal Care Plan so I can gather important information about your child including emergency contact details, clearly in mind, medical requirements, abilities, routines and favourite activities. I will ask you to review this information regularly to ensure it's up to date.

Any information provided will be treated as private and confidential.

Please refer to my Privacy Notice and Confidentiality Policy for further details of my data processing and handling procedures.

Personal & Family Details

Child's Full Name: _____ Date Of Birth: _____

Home Address: _____ Lives with: _____

Tel: _____

Mother's Name: _____ Day Time Tel: _____
Address: _____ Mobile: _____
(If different from child) Email: _____

Father's Name: _____ Day Time Tel: _____
Address: _____ Mobile: _____
(If different from child) Email: _____

Other Carer: _____ Day Time Tel: _____
(General responsibility) Address: _____ Mobile: _____

School / Nursery: _____ Tel: _____

EMERGENCY CONTACTS

In the event of an emergency I will always try to contact parents / guardians first. If for whatever reason I cannot get in touch with you, please give the names and contact details of two other people I can call.

Name: _____	Name: _____
Address: _____	Address: _____
Tel: _____	Tel: _____

Please confirm that this emergency contact has consented to share their information.

YES NO

Please confirm that this emergency contact has consented to share their information.

YES NO

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Care Plans in the NHS

Score	Y/N	Y/N	Y/N
Bravery Understanding patient and carer's needs and wishes of dedication and support	Silver	Gold	Comments
Care Plans		Care Plan template with input from Care Home Staff	
Care Plan must be in shared care and diagnosis support and social care		Care Plan template with input from Care Home Staff	
Understanding of Advance Decisions, Advance Directives, LPA and LAC		Care Plan template with input from Care Home Staff	
Communication		Care Plan template with input from Care Home Staff	
Care Plan must be in shared care and diagnosis support and social care		Care Plan template with input from Care Home Staff	
Understanding of Advance Decisions, Advance Directives, LPA and LAC		Care Plan template with input from Care Home Staff	
Community Engagement		Care Plan template with input from Care Home Staff	
Care Plan must be in shared care and diagnosis support and social care		Care Plan template with input from Care Home Staff	
Environment		Care Plan template with input from Care Home Staff	
Understand about dementia Identify signs and symptoms		Care Plan template with input from Care Home Staff	

NHS

Score	From Before (Assess)	In Between Diagnosis	During Care Plan (Plan)
Bravery	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support
Care Plans	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support
Communication	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support
Community Engagement	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support
Environment	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support	Understand patient and carer's needs and wishes of dedication and support
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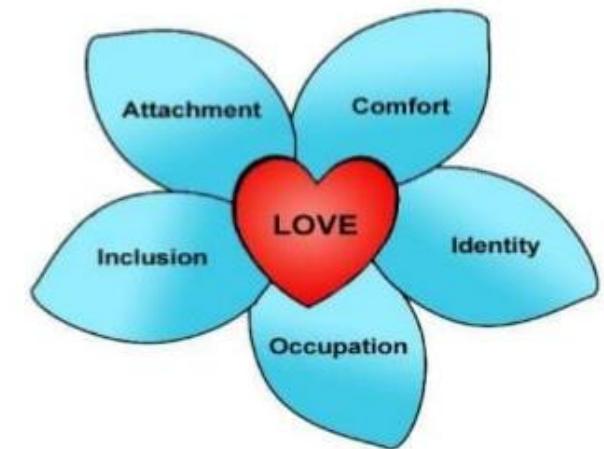
NHS Personalised Care Plan
Giving patients control of their own health

Patient Details	
Name: JONES,	
Address:	
Home Tel:	Date of Birth:
Mobile Tel:	NHS Number:
Residential status: No events found.	
Home access information: No events found.	
Main language: unknown	
Door access keycode: No events found.	
GP Practice Details	
GP:	
Practice name:	
Practice address:	
Practice telephone:	
Practice Manager (if applicable): No events found.	
Practice Co-ordinator: No events found.	
Other people involved in care	
Other professionals:	No events found.
Patient Carers	
Patient Carers:	No events found.
Patient Carers:	No patient carers recorded.

Next of Kin (and other contacts)

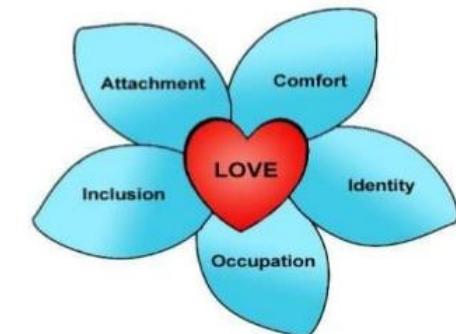
Person Centred Care

- Tom Kitwood and person centred dementia care philosophy
- Person centred care in the NHS (and other services)
- The ideal:
 - A designated key worker
 - An individual relationship
 - Excellent knowledge of the person, their history, background, needs and hopes
 - Covering all key areas: the TK flower as well as health needs
 - Regular reviews and updates



Care Plans and Planning

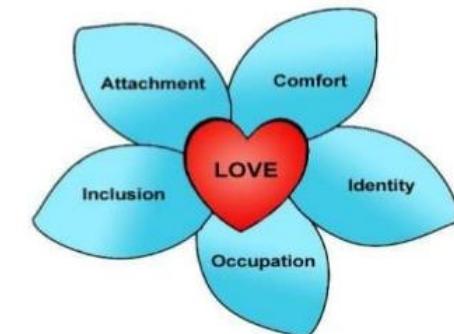
- Operationalising the aspiration in the NHS
- Realities in an underfunded system
- Translating principles into forms
- Care plans as performance indicators
- Ensuring that boxes are ticked
- Some examples of minimising time and resources used
 - The online system form completion
 - The doctor's letter counts



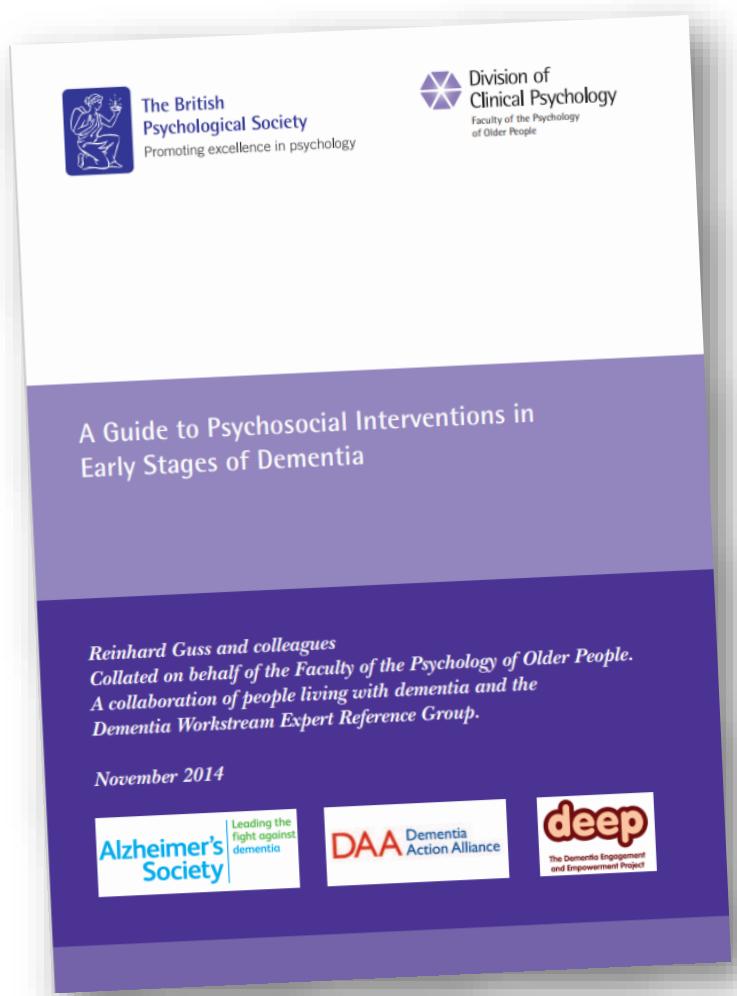
Care Plans and Planning

Some further issues

- Whose job is the care plan anyway?
- Who has got the care plan?
- Who ensures the actions happen?
- How to access knowledge and resources when faced with unfamiliar conditions and needs?
- How to follow up and review without long-term relationships?



FPOP Guide to Psychosocial Interventions



Can be accessed through the British Psychological Society shop and DEEP website

Examples of evidence based non-drug treatments

The list of interventions

- Advance Care Planning
- Dementia dogs
- Assistive Technology (support and advice)
- Cognitive Behavioural Therapy (CBT)
- Cognitive Rehabilitation (CR)
- (Maintenance) Cognitive Stimulation Therapy (CST)
- Compassion focused therapy (CFT)
- Cognitive Training (CT)
- Counselling and Psychotherapy
- Creative Arts Therapies
- Dance and Movement Therapy
- Dementia Advisors (support from)
- Dementia / Memory Cafés
- Drama Therapy
- Family / Systemic Therapy
- Horticultural Therapy
- Involvement Groups
- Life Review Therapy
- Life Story Work
- Meeting Centres
- Museums, Art Galleries and Heritage Sites
- Music Therapy
- Occupational therapy
- Participatory Arts
- Peer Support Groups
- Post-Diagnostic Counselling
- Post-Diagnostic Groups
- Reminiscence
- Signposting
- Specialist Information
- Specialist services for people with YOD
- Speech and language therapy
- Stress / Anxiety Management

Examples: New interventions in 2nd edition

- Compassion Focused Therapy
- Speech and language therapy
- Horticultural therapy
- Participatory arts
- Meeting centres
- Creative arts therapies expanded:
 - Music therapy
 - Drama therapy
 - Dance and movement therapy
- Dementia dogs
- Museums, art galleries and heritage sites



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Example: Community resource

- The Meeting Centre Approach



The Meeting Centre Support Programme UK

What is the Meeting Centre Support Programme?
It is a local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people and families affected by dementia.

At the heart of the Meeting Centre is a social club where people meet to have fun, talk to others and get help that focusses on what they need. Meeting Centres are based on sound research evidence on what helps people to cope well in adjusting to living with the symptoms and changes that dementia brings.

Evidence-based, local support for people and families living with dementia

What's the evidence that this helps people?

There is good evidence both from Dutch research and recent UK research that people attending Meeting Centres experience better self-esteem, greater feelings of happiness and sense of belonging than those who don't attend. Those who attended most regularly showed fewer of the more distressing symptoms of dementia and a greater feeling of support. Family carers also experience less burden feel better able to cope. People with dementia and carers report high levels of satisfaction with the programme, seeing it as an important way of keeping active and feeling supported.

Community Engagement and finding our more



Many towns have initiated Dementia Friendly Communities.

Meeting Centres build on this. They generally start from a care organisation or group of people recognising that there is a need for more structured support for people affected by dementia in a local community. It is not really important who comes up with the idea to initiate a Meeting Centre, because collaboration with other organisations is essential to getting the initiative off the ground.

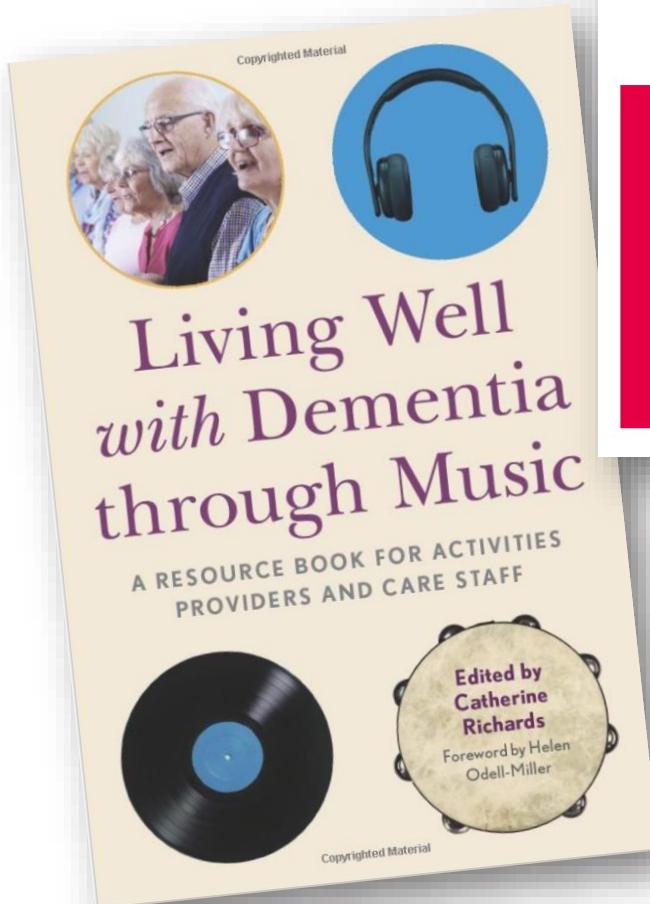
Compassion Focused Therapy

- **Compassion Focused Therapy** is a type of talking therapy used to treat a range of psychological difficulties. It can help overcome anxiety, depression and the emotional consequences of stressful life events, such as living with dementia.
- It concentrates on ways we treat and talk to ourselves and helps to develop a 'compassionate mind' towards ourselves and our approach to life and the world around us.

What is the evidence?

- Craig, C, Hiskey, S, Royan, L, Poz, R & Spector, A. (2018) Compassion Focused Therapy for People with Dementia: A Feasibility Study. *International Journal of Geriatric Psychiatry*. Dec;33(12):1727-1735. doi: 10.1002/gps.4977
- Collins, R, Gilligan, L & Poz, R. (2018). The evaluation of a compassion focused therapy group for couples experiencing a dementia diagnosis. *Clinical Gerontologist*, 41(5), 474-486, doi: 10.1080/07317115.2017.1397830
- Craig, C., Hiskey, S., & Spector, A. (2020). Compassion Focused Therapy: a systematic review of its effectiveness and acceptability in clinical populations. *Expert Review of Neurotherapeutics*. doi:10.1080/14737175.2020.1746184

Music Therapy – Arts based programmes



This screenshot of the Arts4dementia website features a red banner with white text: 'Arts opportunities to empower people affected by dementia in the community'. Above the banner is the Arts4dementia logo with the tagline 'Empowerment through artistic stimulation'. The navigation menu includes links to Home, Art Wednesdays, Events & Workshops, Social Prescribing, Training, Resources, Dementia Friendly Venues, About Us, A4D Gallery, My Profile, and Search. On the right, there are buttons for 'Find events', 'Post an event', and 'Support us', along with social media icons. Below the banner is a photo of a woman dancing. A call-to-action box on the right says 'JOIN OUR BRAND NEW PROGRAMME' for 'Dance for Brain Health: A4D Dabke Folk Dancing with Shobana Jeyasingh Dance'. At the bottom is a diagram of a brain highlighting the medial prefrontal cortex.



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Cognitive rehabilitation

Goal-oriented Cognitive Rehabilitation in Early-Stage Alzheimer's Disease and Related Dementias:
Multi-centre, Single-blind Randomised Controlled Trial

- ▶ **Aim:** To determine whether goal-oriented cognitive rehabilitation is a clinically-effective and cost-effective intervention for people with early-stage dementia and their family carers.
- ▶ **Chief Investigator:** Professor Linda Clare
- ▶ **Funder:** UK NIHR, Health Technology Assessment Programme
- ▶ **Participants:** People diagnosed with Alzheimer's disease (AD), vascular dementia, or mixed AD and vascular dementia (with a carer); MMSE score of 18 or above (or equivalent)



A Special Issue of the journal
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Neuropsychological
Rehabilitation



Cognitive Rehabilitation in Dementia

GUEST EDITORS
Linda Clare and
Robert T. Woods

Example: Peer support and involvement groups



The UK Network of
Dementia Voices



Innovations
in Dementia



DEEP Guide

deep
The Dementia Engagement and Empowerment Project

Dementia words matter: Guidelines on language about dementia

Key messages

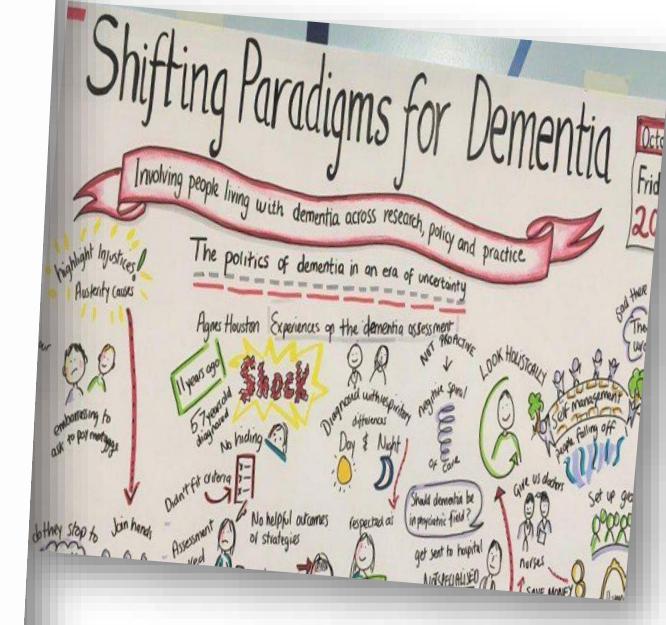
- This guidance is for journalists, organisations and communications departments.
- The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.
- People with dementia prefer words and descriptions that are accurate, balanced and respectful.

Dementia is discussed more regularly now in the media - both on television and in newspapers and magazines. The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. People with dementia prefer words and descriptions that are accurate, balanced and respectful.

These recommendations are written by 20 people with dementia who came together for a day in Liverpool to discuss the words that are used about dementia.

A brief guide co-produced by The Dementia Policy Think Tank (member group of DEEP) & Innovations in Dementia CIC
Authored by Philly Hare (Winter 2016)

deep The UK Network of Dementia Voices **id** Innovations in Dementia



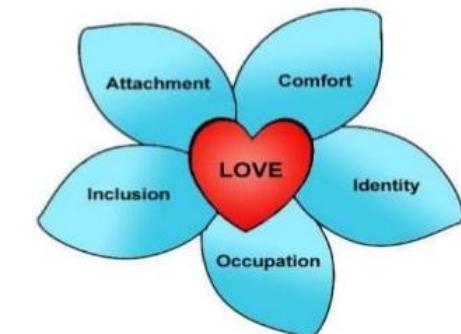
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How a toolkit can help

- Information and education
- Key headings and issues
- Copy and paste relevant sections
- Anything that saves time/resources
- Use by any agency/profession
- Make your own care plan
- Accessible for family and carers





**Do you have
any questions?**



**Thank you
for joining us**



youngdementianetwork.org/our-webinars