Welcome to Indiviuali-tea

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

youngdementianetwork.org/our-webinars
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% of 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.
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

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

Services experienced as positive
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

### Patient / Service User: Keith Oliver

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

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<tr>
<td>Medication</td>
<td>Galantamine MR 24mg and Memantine 10mg once daily</td>
<td>Canterbury and events as needed</td>
<td>Reduce symptoms of Alzheimer’s disease</td>
<td>Collect every two months</td>
<td>Maintain function without adverse side effects</td>
<td>Indefinite</td>
<td></td>
</tr>
<tr>
<td>Inter-generational support from psychology students, volunteers</td>
<td>Formal and informal meetings</td>
<td>Support with project work and travel, positive conversations, connecting with former roles</td>
<td>Pool of students/volunteers with supervisors</td>
<td>Once or twice per month</td>
<td>On me — helping young people, enrich their placement, offer guidance, experience, friendship</td>
<td>On them — being a recipient of the above, encouragement, interest</td>
<td>Annual review</td>
</tr>
<tr>
<td>Primary care dementia review</td>
<td>One to one</td>
<td>Remote consultation or GP surgery</td>
<td>Check BP and needs</td>
<td>Annually (February)</td>
<td>Maintain physical health and stable blood pressure</td>
<td>Indefinite</td>
<td></td>
</tr>
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### our Care Plan

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<tr>
<th>Patient / Service User: Keith Oliver</th>
<th>Care coordinator / Consultant:</th>
<th>GP:</th>
<th>Review Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity</strong></td>
<td><strong>Delivery</strong></td>
<td><strong>Location</strong></td>
<td><strong>Purpose</strong></td>
</tr>
<tr>
<td>Body Well</td>
<td>One to one</td>
<td>Blean</td>
<td>Spinal treatment and muscular and joint massage</td>
</tr>
<tr>
<td>Support from key friends</td>
<td>One to one</td>
<td></td>
<td>Emotional support to and from key friends</td>
</tr>
<tr>
<td>Social walking</td>
<td>One to one with PPE / distancing</td>
<td>Familiar local routes</td>
<td>Physical and mental exercise</td>
</tr>
<tr>
<td>Talking therapy</td>
<td>2 x 30 mins per week – Tree of life focus</td>
<td>Virtual by Messenger video call / in person</td>
<td>Regular forum to share concerns and develop strategies</td>
</tr>
</tbody>
</table>
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 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
Care Plans in the NHS
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
Example: Community resource - The Meeting Centre Approach

**What is the Meeting Centre Support Programme?**
It is a local resource, operating out of ordinary community buildings, that offers ongoing 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 focuses 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?**
Music Therapy – Arts based programmes

Arts opportunities to empower people affected by dementia in the community

New research indicates that the medial prefrontal cortex may serve as a hub where music, memory and emotions meet. It is also one of the last brain regions to atrophy in Alzheimer’s patients.

Medial prefrontal cortex
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)
Example: Peer support and involvement groups

Our Dementia, Our Rights

Dementia words matter: Guidelines on language about dementia

Key messages:
• The language we use is important as it shapes people’s views and perceptions.
• The words we choose can influence how people feel about themselves.
• They can also affect how people support and care for people with dementia.

Dementia is described using a wide range of terms that can have different meanings and implications. The language we use in this guide is intended to help people understand and reflect on the impact that this has on their own experiences.

These problems are experienced by people with dementia and their families. They can lead to a reduced quality of life for both the person with dementia and their family.

Dementia is a condition that affects the brain and can lead to a range of symptoms, including memory problems, difficulty with communication, and changes in behavior. It is important to use language that is appropriate and respectful when discussing dementia.
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