

## Mapping the Dementia Journey

### Scenario 3 – The carer of a person living with dementia needs to go into hospital for planned surgery

Not known to Services, maybe no diagnosis	Known to Services, care package in place
<ul style="list-style-type: none"> <li>• No diagnosis of dementia – not presented for diagnosis.</li> <li>• Carer is likely to neglect/delay interventions of own health needs.</li> <li>• Dementia is not age specific – need more information and signposting for younger patients including diagnosis.</li> <li>• Admiral Nurses/Positive Steps Programme – involves planning for the future to consider care in a carer crisis.</li> <li>• Carer will call Alzheimer’s Society for advice on what to do – can be planned in advance - within weeks of appointment due.</li> <li>• GP or Practitioner contacts Alzheimer’s Society for advice.</li> <li>• GP – could be the link person that is aware of the caring situation – GP’s carers register? <b>Primary Care.</b></li> <li>• Registration of carers at GP surgery.</li> <li>• MECC – Ask patients about their circumstances at every opportunity, capture info and systems so that it follows them.</li> <li>• Posters/Information Boards within GP surgeries.</li> <li>• Ask the question! Professionals need to ask consistently whether people who are older might have concerns/issues around dementia to increase diagnosis/no’s.</li> <li>• Why do carers not ask for help? GP/primary care appointments have limited time and people are really conscious of not wasting it.</li> <li>• Where to raise awareness of services available.</li> <li>• Is there a role for GP’s in asking all their patients whether they care for</li> </ul>	<ul style="list-style-type: none"> <li>• Young carers - how to reach - more likely to be unaware of services available.</li> <li>• Person who already has a care package - much more likely to contact social care or Carers Wakefield or the provider to ask for assistance.</li> <li>• Timescale – time required to assess needs (if not known to Social Care0 is an issue if carer has ‘put off’ seeking support. Better awareness will help.</li> <li>• Multidisciplinary approach in the Hub to look at the holistic support already in place and how this can be increased to support the carers’ situation.</li> <li>• If carer/service user is known to ASC – their needs met by carer should already be identified – making it easier to put in an alternative plan.</li> <li>• Barrier – not enough people (caring for people who are not eligible for ASC) are getting carers assessment in their own right enabling them to be known to ASC and for ASC to ‘step up’ in a crisis.</li> <li>• Advanced care planning for carers - what should happen when.</li> <li>• Use of Emergency Carers Plan to discuss planned as well as unexpected need – signpost to appropriate service.</li> </ul>

<p>someone (and why does something need investigating.)</p> <ul style="list-style-type: none"> <li>• Need to wider engage voluntary community. Sector/community/WDH/Age UK/Carers etc. (Organisations to contact carers facilitate planning.)</li> <li>• WDH engagement to recognise support to give carers.</li> <li>• What is the support that is there in this situation – and will it cost money? Carers' questions.</li> <li>• Emotional roller-coaster – guilt/fear/failure.</li> </ul>	
<ul style="list-style-type: none"> <li>• GP's to include info re care situation in referral letters.</li> <li>• Alzheimer's Society will signpost to ASC re respite options.</li> <li>• Believe going in for Day Surgery but haven't planned for worst case scenario.</li> <li>• Having a 'befriender' early on to build up a relationship so they can step in for respite.</li> <li>• Access to respite admission if the best option can be difficult for the carer to organise and availability of respite beds in care home sector often minimal.</li> <li>• Decline of dementia when moved away from own home environment.</li> <li>• Respite would always be the last solution to be considered by Social Care – other ways would always be explored first.</li> <li>• Improved outcomes seen often in a more adaptable care package not respite period.</li> <li>• Need to consider first assessment of needs in most appropriate environment – does it meet legislation etc. DDL's etc.</li> <li>• (Surgeon) Decision to put on waiting list for operation. Question about – Who's at home? How will you manage?</li> <li>• Point of contact for carer e.g. Care Navigation Coordinator from a commissioned agency.</li> <li>• Cost of respite care prevents carers considering it.</li> <li>• Uncertain date of operation makes arranging respite for person with disability. Carers often have responsibility to arrange.</li> <li>• If the question is asked about caring situation there needs to be an intervention.</li> <li>• Risk of early discharge to ? perceived caring need.</li> <li>• GP referral to contain info regarding caring status.</li> <li>• Self-funding – lost in system as not known to services, therefore no contingency plans in place.</li> <li>• Communicate with the surgeon and ward the implications of cancellation and place appropriately on the list and reduce the risk of cancellation.</li> <li>• Are appropriate questions asked at referral and planning to ensure adequate assurance to carer that time is available for recovery.</li> <li>• Conversations to happen earlier – part of advanced planning – <u>contingency planning</u> for carers (Carer Emergency Plan)?</li> </ul>	

- Person becomes unsettled in an unfamiliar care home/respite environment → Referral to Mental Health Rapid Access Service → Educational support for care home via Intensive Home Based Treatment Team (short term) → long term – Referral to CMHT? for ongoing support (if deemed appropriate).
- Support from surgery pathway to get help as carer for service user.
- At point of being on waiting list.
- Ask as part of surgery pathway – Who is at home? Do you care for any one? What will happen to them?
- Carelink – monitoring equipment available post discharge to alert for falls/motion sensors etc.
- Carelink – medicine dispensers – ensure medication is taken on time – alerts raised if not.
- Self-funding - using money for care - not willing to do so (inheritance).
- Recovery will depend a lot on how well the surgery is planned for, i.e. how dementia patient will be cared for.
- Recover care home for both person with disability and carer so they can recover together – **There may be some possibilities in Wakefield.**
- Referral to care homes from hospital? “Fully mobile” but need evidence of mobility to support care home assessment.
- No worry for relative if person with dementia is safe and cared for.
- Carer reaches a realisation that they aren’t coping and the person being cared for is left in crisis as the carer doesn’t want to be discharged.
- Respite. Person with dementia stimulated.
- After care. Access to rehab. Particularly for care homes – inadequate support for rehabilitation – diagnosis of dementia = no rehab potential. \*Need to encourage mobility.
- Risk of paramedics bringing both carer and person living with dementia into hospital due to risk to safety.
- WDH Carelink – Take a Break service (WDH & private customers) – visiting and care link equipment – response to falls.
- WDH – Home Visiting Service (WDH & private customers) – welfare checks – advocacy – wellbeing support.
- CHC – meet needs in various ways – PHB.
- WDH – independent caring and extra care facilities – meals and domestic service – daily monitoring and support – 41 schemes across district of Wakefield.