



Feedback from Carers

Peninsula Community Health in collaboration
with Alzheimer's Society

Sue Greenwood
Teresa Parsons



Quality care, closer to you

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Dementia CQUIN

3b. Ensure carers of people with dementia and delirium feel adequately supported.

Carer survey - Commissioners and providers will need to agree on the content of the survey and local processes for surveying carers of people with dementia and delirium which should cover the whole health and social care economy.



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Health Fairs



You're invited to our health fair!

Pop along and enjoy a free cup of tea and a slice of cake at one of our health fairs near you!

Monday 27 April, 2pm to 4pm
Crossroads Care Home,
Boscombe, Redruth, TR15 5BP

Monday 18 May, 2pm to 4pm
Launceston Town Hall,
Launceston, PL15 7AR

Monday 1 June, 2pm to 4pm
Falmouth Rugby Club,
Falmouth, TR11 3QG

Monday 14 September,
2pm to 4pm
Wasebridge Town Hall,
Wasebridge, PL27 7AQ

Monday 21 September,
2pm to 4pm
St Mary's Town
Hall, Isles of Scilly, TR23 0LW



With lots of informal advice available about a wide-range of health conditions, from dementia, to diabetes, stroke to respiratory conditions and much more, we'll be able to provide guidance and support to help you and your loved ones.

Come and chat to our skilled teams, take part in a live memory café and let us help support and guide with any health questions you may have.

If you're a carer of the someone who has dementia you'll also have the chance to give us your feedback on how dementia carer support could be improved in Cornwall and the Isles of Scilly.

For more information please contact:
susan.greenwood2@pch-cic.nhs.uk or call
01637 834806.

Created collaboratively two sets of questions which were used as a stimulus to aid our conversations

1 Clinically based Community Hospital Services

2 Based around services available in the Community

Feedback

What's working well

Listening to other carers helps as their experiences can enlighten and support
 Excellent care/re-hab at community hospital and physio input
 Admiral Nurse, very good (but tremendously high caseloads, more needed)
 Person with dementia 'keeping himself busy' clubs, interests
 Made friends as a couple with another couple at the memory cafe
 I'm getting better at accepting things instead of trying to change them
 Free courses for carers PROMAS
 TAPS/Dial a Ride, excellent transport service
 Community hospitals starting 24hr open visiting
 Newquay hospital; trains all staff in dementia awareness and offers memory café's as do other community hospitals
 St Day Church Hall, Friday's Singing very stimulating and enjoyable, as is 'Singing
 CPN very nice
 Welcome home service (Volunteer Cornwall) on discharge
 Support Worker from Age UK very good
 Memory café is a 'god send'
 Fact Sheets Alzheimer's Society – very helpful
 PCDP very helpful, wonderful

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Feedback

What's not working so well and what were some of the concerns

What about 'cutbacks' and financial constraints – especially post-election?
 Can be very 'wearing' and frustrating, very tiring
 I feel like my whole life is circulating around my mother
 Poor communication with relatives around acute care decision making
 Inappropriate early discharge
 Inconsistency of health/care experiences (acute wards)
 Lack of information for care from health (CFT)
 Lack of emotional support for carer
 When information sent from organisations can be out of date (e.g. courses)
 Would like community hospitals to be place to receive support – would need help with transport
 Lack of information from GP
 I dread going home sometimes as he is different with me
 Sometimes think, 'what do I do now?'
 You are 'out on your own' it's more than loneliness
 Lack of public transport so can't get to community hospital
 Exhaustion/sleep deprivation putting carers health at risk
 Didn't know about carers allowance for 2 years'
 Haven't had carers assessments and if had one before has not been reviewed
 Staff changing all the time (especially CPN's)

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Feedback

Need more stimulating activities in community for people
 Need sitting and befriending in the home service and/or 'drop in' for this
 Still waiting for OT Assessments (linked to post-diagnosis visit)
 You have to 'keep on' and 'keep on' to get help, you shouldn't have to fight
 Left without support, no contact for carer
 Haven't got time to even have conversations on phone, such as a telephone befriending
 Many shops do not have toilet facilities
 No support for carers, where they can go without cared for person
 3 week wait to see own GP or need to book 4 weeks ahead in some cases
 Day Care £30 - £60, unaffordable
 Worry about giving responsibility to someone else to care for love one
 Want loved one to be with someone who knows what they are doing
 'The hardest thing I've ever had to do'
 I am tired and up throughout the night – I have to sleep with mum to keep her safe
 Funding keeps coming to an end and support 'piece meal'
 Carers assessment – long wait
 No offer of carers assessment – been caring for 4 years
 Don't know how to complain if feel receiving poor or no service
 No response from toe-nail cutting service (4 weeks on) and GP practice doesn't know about service
 After diagnosis, 'shoved out into the community'
 No PCDP in Launceston area
 No central point of contact
 Post diagnosis – would like contact within short specified time period face to face

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Dementia CQUIN

Where we could we took away some immediate actions

This included :

Contacting Social Care

Providing 1 to 1 support from the Alzheimer's Society Support Workers

Contacting agencies and providing up to date information

Myth Busting

Just a telephone call to follow up and to ask how someone was

Sending Information requested

Listening

Telling carers that its ok to ask for help

Personal and Professional Reflection's

Understanding that the people who met with us were desperate for some help and someone to listen to them.

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Dementia CQUIN

Next Steps

Share our experience

Review the feedback within my organisation

Present findings to Commissioners as part of our CQUIN Evidence

Use the feedback to inform service re designs collaboratively across Health/
Social Care and 3rd Sector agencies

Acknowledge the role of carer's and how important it is that we support them

Collate the feedback and present to our Commissioners

Thank you