

Summary Report: ***Alzheimer's Society Dementia Support Workers***

Wednesday 8 July 2015 | 2pm
Hazelmeir Day Centre, Cleeve Court, Bath

Attendees

Barry Grimes, Communications Manager, BaNES CCG
Laura Marsh, Commissioning Manager for Long Term Conditions, BaNES CCG

Also in attendance:

Chris Atkinson, Operations Manager at the Alzheimer's Society
Two dementia support workers (DSW)

Meeting Summary

Barry and Laura gave an overview of the your care, your way review and explained the nine key themes that had emerged from Phase One of the engagement. They then led a discussion on what could be done to make improvements in these nine key areas.

Comments

- People don't want too many people involved in their care. It gets confusing, but can it be avoided?
- People who see a DSW tend to focus specifically on their dementia and not their other health needs.
- People feel overwhelmed with information – how do they know what's relevant?
- The real skill is to identify specific needs and match people to appropriate services.
- People won't use services if they have to pay for them e.g. day centre
- People are proud and want to remain independent

- Perceptions of how well people are managing their own care differ greatly
- Services are often more relevant for carers
- People need to engage with those who have had direct experience of their specific situation e.g. peer support
- Peer support groups are vital and can often be delivered at low cost in a sustainable way
- People have been told about the services available to them but many people are scared to join groups and want something personalised
- After diagnosis, people lose confidence and don't want to engage with groups. Need to rebuild confidence and relearn skills that have been lost
- Being a new person in a group is hard but all starting together makes it easier to build relationships e.g. if people go through a course together and continue to socialise after the course has finished
- Need a familiar face at the group to introduce them and pick out potential good connections. Also need to address practicalities like transport and carer cover
- When people attend local groups and then bump into familiar faces in the street or in the shop it makes them feel like part of the community
- How do we give people the courage to join a group? Recognising that people aren't feeling 100% when they join a group – they're going for support to get better
- DSWs provide support plans but they need to be multidisciplinary. People forget who they've seen and lose track of where they are in referral process. DSWs are not kept up to date on the latest situation
- People need to take personal responsibility for seeking out information
- Dementia Connect – part of the Alzheimer's Society website, like an information prescription
- Talking Point – a peer support online chat room moderated by the Alzheimer's Society is very popular. It gets a lot of activity at 3am-4am!
- Face to face is the best solution for those who don't like technology
- The CCG needs to understand what % of old people are using technology so they can commission the right services for them

- Isolation can feel worse when in a big crowd
- Isolated rural communities are often better at social groups/support than suburbs
- Waiting lists for services e.g. day centres are a problem. Need to increase capacity
- Need single point of access for local services e.g. one phone number like 111 for local services. People find it easier to speak to someone on the phone. It could be staffed by volunteers who can take the time to give advice and have a chat
- It would be better if there was a central call centre that could refer new cases to the DSWs and then the DSW calls patient. Cuts out all the referral paperwork time as well.
- What about online chat and out of hours support?
- People need a point of contact they can reach at any point on their journey when they get stuck e.g. DSW who could make referrals on behalf of patient. People might not need the service most of the time but it's comforting to know it's there when you need it
- "discharge" sounds too formal – sounds like "you're on your own now". Needs to sound less final e.g. "handover"
- Need to be more proactive with transitions; don't just leave people with a leaflet – give them a follow up call
- Services are nervous about providing indefinite ongoing support but it would prevent people from having to cling on – DSWs offer this service and they are not overwhelmed
- It's good to get through to a real person on a mobile rather than a 0800 call centre. People recognise it's not 24/7 as long as you make the voicemail message clear
- People often have to wait long times for referral letters. Getting call within 2 days keeps it instant and moves you onto the next stage quickly
- There is a fine line between being a friend and a professional but it's good to make services feel more personal
- Clinicians are often scared of giving out a mobile number but it often works out ok. People are sensible and don't abuse the system. The CCG should trial this model of ongoing support in another setting other than dementia care.