health and social care

How can we support people with dementia and their carers?

Come and have your say

Wednesday 29th April 2009

Devizes Corn Exchange SN10 1BN

The consultation was hosted by the Wiltshire Involvement Network (LINk), Supported by HAP UK, the Wiltshire & Swindon Users Network and Age Concern. About 60 people representing 14 Voluntary Sector Organisations in Wiltshire attended the event.

There was a Vote on the Election process on the composition of the Core Group, which was agreed by the Majority.

Questions and responses from the round table discussions:

Question 1	**What needs to be done to establish early diagnosis of dementia?**
Question 2	**What kinds of support services do people with dementia need?**
Question 3	**What kinds of support services do carers of people with dementia need?**

TABLE 1: Facilitator – Terry Singleton Scribe – Anne Rose

Question 1: What needs to be done to establish early diagnosis of dementia

- Health visitors for the elderly at request from patient, family, carer or friend.
- Prompt assessment of patient & Carer needs.

- GP training to be made aware of dementia.
- A simple test to be used at home to get an idea as to whether there may be a problem.
- Techniques to get to more shy people who will not admit to a problem.
- GP to take patient concerns seriously.

Question 2: What kinds of support services do people with dementia need?

- Consistency of care workers and to be well trained.
- Sufficient numbers of beds in nursing homes for dementia patients.
- Prompt assessment for carers needs.
- More public awareness of the needs of dementia sufferers and carers.
- Make sure all care workers are trained.
- Employers all need to be trained and should monitor their care workers.

Question 3: What kinds of support services do carers of people with dementia need?

- Support services to support a long distance carer.
- One phone number for help/signposting-direct contact.
- Person on end of phone must be an expert and understanding.
- Well advertised for each authority.
- Planned respite for carers.
- Pensioners need to get some form of monetary recognition of their carer role.
- Independent financial people to monitor that money.
- More money to be available for training of care workers and letting carers know what is available.

TABLE 2: Facilitator – Martin Fortune Scribe- Emma Bollen

Question 1: What needs to be done to support the early diagnosis of dementia.?

- Legal definition of dementia i.e. for benefits.
- Medical definition only.
- GPs better educated. Regular contact of patients, if no family, has to be GP.
- Awareness Publicity.
- Social care is not free e.g. care homes.
- Support Alzheimer’s.
- Hospital Discharge no support in Wiltshire only basic support.
- Voluntary agencies to bring support package together for hospital discharge. Multi agency.

- Key Point
- Education training and awareness of early diagnosis.

Question 2: What kinds of support services do people with dementia need.

- Awareness, knowledge and information especially carers.
- Individual assessment of need.

Question 3: What kind of support services do carers of people with dementia need?

- Respite care.
- Information for carers.
- Voluntary agencies e.g carers support Age Concern.
- Key Point. Information knowing where to go for information at every stage along the way.

TABLE 3: Facilitator- Paul Howard Scribe- Maureen Crossley

Question 1: What needs to be done to support the early diagnosis of dementia?

- Encourage people to come forward (eg. To GPs) and report on Dementia.
- Recognition, Assessment and Referral.
- Recognise younger people can also be sufferers.
- Place patients in more appropriate wards.
- More local provision to aid diagnosis.
- More specialists to diagnose.
- More memory clinics.
- Emergency services need to recognize dementia and refer appropriately and involve families (if there are any) Training issue?

Question 2: What kinds of support services do people with dementia need.

- Adequate care, continuity of care, max 8 carers per week if cared for in the community. Carers need monitoring by care agencies.
- Training should include new carers shadowing familiar ones.
- More carers who understand client's language.
- Carers to follow the care plan.
- Better training, supervision and scrutiny of carers.
- A dedicated phone and helpline number at County hall for when carers don't turn up or if they are not carrying out the Care Plan. Don't leave people to phone the agency.

Question 3: What kind of support services do carers of people with dementia need?

- Time for a bath, a meal, to open mail, shop, support in a caring role ie. Respite
- Need one person to act as co-coordinator
- Ensure people know their rights.
- Better information e.g. discharge from hospital – what's available.

- Need more funding!
- Helpline for neighbours and all carers etc. who may accidentally becoming carers.
- Extra help for couples who are both users AND carers.

TABLE 4: Facilitator - Valerie Thomas Scribe - Sharon Daws

Question 1: What needs to be done to support the early diagnosis of dementia?

- Need more staff in the dementia field.
- Training specific booklet available in June 2009.
- Going to GP for referral – more information needed.
- Also GPs need correct training and be bale to refer to the correct specialists.
- Regular health checks could highlight dementia.
- In need of more clinics in Wiltshire.

Question 2: What kinds of support services do people with dementia need.

- Continuity of care – there is no system in place. Why do carers change so frequently?
- More day activities/centres and befrienders. Safety issues?

Question 3: What kind of support services do carers of people with dementia need?

- More information and support
- Regular respite for carers and waking carers needed. Individual budgets would help in this case.
- Support services need to be improved.
- Monitoring of care agencies and inspections of domiciliary and homes.

TABLE 5: Facilitator – Joyce Morris Scribe – Kevin Gaskin

Question 1: What needs to be done to support the early diagnosis of dementia?

- Early Diagnosis
- Awareness
- Education

- Training for GPs
- Allow carers to be involved in the process of referral and diagnosis.
- Appointment of LINK workers and carer liaison persons in GP practices.
- Publicity – recognizing the signs (like the FAST adverts)

Question 2: What kinds of support services do people with dementia need.

- Support services for people with dementia.
- Information
- Access to people who understand the information and can translate it.
- Befriending service

Question 3: What kind of support services do carers of people with dementia need?

- Support services for carers.
- Crisis team manned by people who understand dementia.
- Knowledge about available service. E.g. sitting service, specialist hotels.

TABLE 6: Facilitator - Mary Nash Scribe - Mary Wilson

Question 1: What needs to be done to support the early diagnosis of dementia?

- There are services but not enough. Need for knowledge of that to give access – clearing house to direct people rather than specialist experts in every surgery.
- More education on dementia.
- Need to bring this to the attention of GPs.

Question 2: What kinds of support services do people with dementia need.

- Support – help to fill in forms for funding. There is chaos if borders crossed.
- Uniformity of support services.
- Electronic tagging.
- Clear Language speaking Carers. Carers to be made aware of food/cultural differences.
- Cultural differences – both ways – awareness of different cultures.
- Day care centres for those with dementia.
- GPs need to provide info on day centres etc.
- Care should not be cancelled due to lack of funds.
- Continuity of care.
- Lack of funding.

Question 3: What kind of support services do carers of people with dementia need?

- Respite care – need to talk to someone.
- Carers older – rural – help with transport.
- Need for financial assistance between cancellation of government funding and funding elsewhere. Carers need back up.

TABLE 7 Facilitator – David Evans Scribe – Mary Rennie

Question 1: What needs to be done to support the early diagnosis of dementia?

- Remove the stigma which surrounds dementia – fear of dementia is a real problem, as is “covering up” by partners / relatives
- Investigate what is the problem behind the lack of support available in Wiltshire – is it lack of funding, lack of trained staff (including GPs)
- GPs are generalists and need more education in the field of dementia
- How do we get beyond the “it’s your age” response from GPs
- We need more information about the services that are available – there is a nagging doubt that the authorities don’t want to open the floodgates
- Improve access to support groups
- Ensure money available is fairly allocated and not a “post code lottery”
- Involve younger people

Question 2: What kinds of support services do people with dementia need?

- We need to raise the general understanding of the condition
- People need to be appropriately cared for, have a happy quality of life, a sense of control over their own lives i.e. give them options
- Respect the individual - remove the “does he take sugar” approach which is all too prevalent
- People need companionship and befriending – loneliness is a big problem
- Support from families is on the wane because of cultural changes
- Day Centres
- Continuity and consistency of care – service organisation and administration needs to be improved
- Support staff should be directly hired by the authorities to improve control and training
- Support staff are under pressure with lack of funding and hours cut – expectations need to be managed
- Bring back uniforms for support staff
- Use appropriate language – not “customers”

Question 3: What kinds of support services do carers of people with dementia need?

- Better coordination of support – no focal reference point

- List of where to go when certain things happen
- Services are fragmented – carers do not know how to access them – they need a clear guide to services available and who to go to access them
- Carers need to be respected and treated with dignity
- Acknowledge the double burden of younger carers who have elderly parents and young families.

TABLE 8 Facilitator - Jo Bell Scribe – Linda Harris

Question 1: What needs to be done to support the early diagnosis of dementia?

- GPs ‘blockage’ – need to take notice. Person has to make appointment themselves – not acceptable. Data Protection Act prevents family members from doing this for them. GP is first point of contact. What if you are incapable of calling them? Getting 1st appointment can take 9 months – taken 8 years to get mother into a home. Father struggled as no help for him. Devizes office has been a help, but mother has complex needs. Green Lane were not very helpful.
- GPs are a barrier to get through, but once through it can be beneficial. Can be ‘dismissive’ – training for GPs/Practice Nurses – education is very important.
- Aftercare is an afterthought. People are discharged with no care plan. ‘A lottery’ Is it just old age? Do we need a health MOT at a certain age?

Question 2: What kinds of support services do people with dementia need?

- More day centres. Devizes one only open 2 days a week.
- Homes – numbers are limited and if they have more complex needs they won’t take them.
- Centres – ‘one size fits all’. Why should all people be sent to one club/centre.
- Goes back to early diagnosis.
- Support is needed at home. Facilities to make your day/life easier for both carer and patient.
- Patient is still a person.
- Put meal at end of bed in hospital ‘pitiful’ experience/ ill treatment in hospitals.
- Nurse struck off – has full support.
- More drugs and more investment – what is the 18 million for.
- An ageing population – problem will escalate. What will happen when we get there? We know that they need to make a start, needs to be talked about.
- Improvement at Green Lane – ‘Awful’ across the board.

Question 3: What kinds of support services do carers of people with dementia need?

- More time out. I was telling people in Green lane what to do. Learning fast.
- More respite beds available.
- Not advertising what they do
- Awareness needed of what is available now.
- Signposting, leaflets needed. Having to do internet research instead of local resources.
- When a diagnosis is made someone needs to drip feed what is available for carers. Someone whose sole role is to provide support in a language they understand. No Jargon!
- Advocates to work on people's behalf. People who have been through it to give advice.
- Empathy is very important – someone on end of phone.