healthwatch
Shropshire

Dementia services - engaging for the future

A collaborative project to refresh the Shropshire Dementia Strategy Action Plan

November 2016

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Introduction

Healthwatch Shropshire is the independent champion for people who use health and social care services in Shropshire. It was created under the Health and Social Care Act 2012. It helps to ensure that everyone gets the best from their health and social care services, and that those services are as good as they can be and work in a joined up way.

Healthwatch Shropshire's aim is to give patients, service users, carers and the wider public a real say in the way health and social care services are run. The mission is to be the recognised independent voice of the people of Shropshire in seeking to improve their experience of health and social care services.

In Shropshire the Dementia Strategy has been implemented through an Action Plan. The Dementia Strategy Action Plan has a life span of 2014-16 and has been criticised for being complex, long and lacking in co-production with the people it is intended to support. There is concern that it is not person-centred enough and lacking in focus on positive outcomes.

Healthwatch Shropshire was commissioned by the Director of Public Health in Shropshire Council to collaboratively produce a refreshed Dementia Strategy Action Plan to take effect from April 2016.

The timing of the project was delayed until Autumn 2015 as it was discovered that the West Midlands Association of Directors of Adult Social Services (WMADASS) were undertaking a survey across the region with a focus on dementia post diagnostic support. In the Spring and Summer of 2015 WMADASS undertook two surveys of providers, and carers and people living with dementia. The survey demonstrated that thought there is some good news in the responses to the survey there is inconsistency in provision and the responses prompted a number of questions for future consideration including:

- Are relationships between providers strong enough to deliver the pathways?
- Is primary care playing a big enough role in diagnosing dementia?
- Are we providing the right level of information at the right time throughout people's pathways?
- Is the use of Dementia Advisors as planned?
- How can people with dementia have more choice and control over their care?
- How can we improve access to transport to reduce this being a barrier to accessing services?

The findings of the survey were used to inform this project locally in Shropshire. Unfortunately the response rate was low for Shropshire but the report can be read here.

Healthwatch Shropshire receives feedback on services for people with Dementia on an on-going basis and in May 2015 made services for people living with dementia and their carers the focus of the monthly "Hot Topic". Feedback is mixed and illustrates the variation in experiences of care by people living with dementia and their carers, both in their care homes and in care settings.

Public health information shows that over 4,000 people in Shropshire are currently (March 2016) diagnosed with dementia. The ageing nature of the population means that this number is increasing, and problems with diagnosis mean that this figure is already likely to be much higher. Undertaking a refresh of the Dementia Strategy Action Plan is very timely.

The Project

The purpose of the project is to inform a refresh the Dementia Strategy Action Plan across Shropshire by raising awareness and encouraging the participation of people living with dementia and their carers in Shropshire. The aim of the refreshed action plan is to improve outcomes for people living with dementia.

In order to gather people's views about the dementia services they use, and the views of the professionals involved, Healthwatch Shropshire was keen to work with partners. Contact was established with the Alzheimer's Society, the Memory Service (South Staffordshire and Shropshire NHS Foundation Trust - SSSFT) and also Help 2 Change (Shropshire Council) and a working group was set up to explore the best way of taking this piece of work forward. The Commissioning Manager in Shropshire CCG was involved initially and following staffing issues engagement was re-established in early 2016.

A project officer was appointed to develop the methodology, in partnership with the working group.

Methodology

In order to achieve true co-production of a refreshed action plan the working group agreed that engagement was needed with

- People living with dementia
- Carers, of people living with dementia
- Services providers, both in the statutory and third sectors

In order to engage effectively it was agreed to arrange focus groups at existing meetings for service users and their carers across the county. It was anticipated that there would be better attendance than by setting up additional meetings.

In order to engage with providers of services to people living with dementia and their carers a "provider forum" was arranged.

The challenge of engaging with general practice and general practitioners was also considered and awareness of the project was raised through short presentations at GP locality meetings across the county and practice representatives were invited to participate in the "provider forum".

The development of a semi- structured survey to use in the focus groups was based on the five objectives used in the Shropshire Dementia Strategy Action Plan 2014-2016.

The five objectives are:

1. Raise awareness & understanding of dementia within communities and, to better identify people with and at risk of dementia
2. Early diagnosis and intervention

3. Accessing high quality care & support
4. People are able to live well and reduce the risk of crisis
5. Ensure high quality end of life care and are well supported

The same questions were asked against each objective:

- What works well?
- What didn't work well?
- What / how could your experience have been improved?
- Where are there gaps?

Permission to attend and hold a focus group was sought from the meeting organisers. To facilitate discussions the objectives were written out, each on a separate paper and responses were written either onto the sheet or a post it note. In addition, some people chose to respond to a separate printed survey, with the same questions, when they were unable to attend an event. These respondents were supported by their workers to complete the survey, when required.

The responses were collated and the findings presented at a dissemination event in March 2016.

In addition, Healthwatch Shropshire was successful in its bid to work with final year medical students from Keele University Medical School. A 16 week project is undertaken whilst the students are based in general practice and the focus of the Healthwatch Shropshire project was to understand how the pathway for people with dementia was managed in each practice. The students developed a questionnaire to inform interviews with a range of practice staff.

The findings from the engagement and also the Keele University project informed the final recommendations set out below which in turn will inform the development of the refreshed Dementia Strategy Action Plan.

Findings

It was agreed that despite the challenges of arranging focus groups at existing meetings and seeking the participation of people living with dementia and their carers that every group was really engaged with the process and valued the opportunity to participate. The benefits of sharing experiences proved positive for the participants and people were keen to know more about the project and its outcomes.

In total 5 focus groups were held at:

- The Mayfair Centre, Church Stretton
- The Care and Share Group, Market Drayton
- The Younger People's Service meeting, Shrewsbury.
- Alzheimer's Society SURPS (Services User Review Panel) Group, Shrewsbury
- The Dementia Café, Oswestry

A county wide "provider forum" was held in Shrewsbury.

The following people shared their views at the events

- 18 people living with dementia
- 29 carers
- 17 providers of dementia services.

Time constraints proved challenging. The groups usually meet monthly and for a maximum of a few hours. The importance of the project was highlighted in advance to the meeting co-ordinators.

In addition a number of people, who were unable to attend an event, chose to respond to the questions in writing and 5 responses were received from people living with dementia and 5 were carers.

The findings from the focus groups are set out below under objectives 1-5, highlighting what respondents think works well, where it isn't working well and where there are gaps. There is some overlap in the discussions under the objectives but as far as possible the outcomes from the discussions are collated under the appropriate headings.

The engagement has provided a richness of information. It was clear that:

"Once you've met one person with dementia…you've met one person with dementia"
From Tom Kitwood.

This is reflected by some contradictions in the findings from individuals (eg too much information vs not enough information) but looked at as a whole there is a synergy in the findings from people living with dementia, their carers and the service providers, which gives us confidence in our recommendations.

The engagement has also identified good practice in the county but this is inconsistent across Shropshire.

Objective 1 Raise awareness & understanding of dementia within communities and, to better identify people with and at risk of dementia

1.1 What works well

Survey responses were positive around the continued drive for an early diagnosis and development of dementia friendly communities. A carer drew comparisons of a cancer diagnosis in earlier times as the' big C':

> *"Parallels to the 1960's and 70's with cancer diagnosis 'The Big C' in that we now know there is lots of cancers and treatments. We now need the same exposure and information of dementia"*

Most carers thought that there is more awareness and were surprised at how supportive people can be once they know a person in their community has a diagnosis. Some commented that a few people in their neighbourhood held an outdated view of dementia. Neighbours can be helpful. Positive comments were more common with people who had lived in their community for many years. One carer said that;

> *"We live in a village both shops and the garage are now aware (of loved ones diagnosis) and supportive"*

Families were supportive too although priority was given to their immediate family and work commitments. One younger person diagnosed with dementia moved to live with their grown up child and young family. A recently retired couple, who moved counties to be nearer to their newly diagnosed older relative, talked positively of service provision in Shropshire that is available to their relative.

Transport was a popular topic for various mixed reasons (see section 1.2) and was mostly commented on by younger people living with dementia. One was confident to walk into town and shop unaccompanied, only using taxi's for special occasions. Another younger person had friends who regularly collected her to go to activities and events they enjoy together. One carer commented that local facilities that they frequented, including a pub and church, were dementia friendly in terms of a welcoming attitude and physical environment. A visit to a bank was a positive experience because the person waiting in the queue was respectful and patient. One carer said that their local supermarket was very friendly, polite and patient when a person is having difficulty with paying at the till.

Service providers highlighted having a proactive Dementia Action Alliance and the involvement of the 'Library hub', the ongoing promotion to make dementia friendly communities through the Dementia Friends awareness raising talks. The development of Dementia Friends and Dementia Champions and proactive promotion by the Diocese of Lichfield to make their churches dementia friendly was identified as good practice by service providers.

1.2 What is not working well

Carers expressed concern that relatives and families generally had no understanding or awareness of dementia. Some said that their friends did not know what to expect. Others commented on a general lack of public knowledge and stigma. A person living with dementia stated that their partner had always done the shopping and that if he had to shop on his own he would need someone with him to support with decisions and tasks. One person commented that:

> *"Dementia is a cruel disease, progressive and surrounded by a general lack of public understanding"*

And:

> *"People don't notice you have dementia because it is not obvious".*

Other comments were about not wanting to be labelled for everyone to know they had dementia unless they had agreed to it.

> *"Some notice my symptoms when I panic".*

Many younger people living with dementia said that their employers and occupational health workers were totally unaware that younger people can have dementia too. Most people agreed that the physical environment of their community was not dementia aware or friendly at all, and highlighted poorly lit and/ or confusing signage or lack of signage. This included supermarkets, shops, GP surgeries and places like bus and train stations. One younger person said that they parked in the wrong shopping bay due to poor directions and lighting.

A carer of an older person living with dementia said:

> *"….Supermarkets can be difficult as my husband looks big and strong. People don't know he has dementia and wonder why he can't help"*

The younger people with dementia said that public transport was not dementia friendly; buses and trains being the most commonly identified. Examples given were poor signage and the lack of obvious advisors on train platforms or bus drivers not recognising the reason for a person's confusion or disorientation. Another said you can end up walking in the wrong direction. This is further exacerbated by people pushing and shoving and large gaps and steps can be problematic and stressful to negotiate. Disorientation can happen to add to difficulties. Similarly, bus drivers may not be particularly helpful because they don't do anything unless they notice outward signs such as shaking or anxiety about the passenger not finding their bus pass.

Service providers' comments highlighted that raising awareness of young onset dementia was not working well and said that there is a lack of integration and co-ordination of services. They also told us they lacked knowledge about the services that are available locally for the people they support. They said there was a lack of local training for people to become Dementia Champions. Some service providers thought that the name of services can be stigmatising too.

1.3. Gaps, opportunities and other comments

It was identified that there needs to be awareness raising for employers and that they uphold their duties and obligations to support employees. Increased awareness and support would keep employees in work for longer and would be a positive outcome.

Providers agreed that for all the services that work well that they need to work well for all localities of Shropshire. There needs to be a drive to improve equity and reduce inequality.

Recommendations

- It was recognised that there was good practice in the county but that it was inconsistent and these inequalities should be addressed
- Dementia Champions and dementia awareness of the staff in doctors surgeries should be developed and GP practices should also be dementia friendly in terms of the physical environment and attitude of workers.
- Dementia awareness and reduction of stigma in communities, services, schools and businesses should be encouraged. The "Big D" could help to reduce stigma as the Big C did for cancer.
- There needs to be awareness raising amongst employers about the impact of dementia to enable support and reasonable adjustments to be made.
- Young onset dementia is currently an issue but as the workforce ages the incidence of dementia amongst employees could reasonably be expected to increase and awareness raising with employers needs to be addressed now.
- Improvements and creative ideas to aid transport especially in rural areas.
- An older person friendly society needs to be developed
- Information needs of individuals should be taken into account including when and how information is required

Diagnosis and intervention were an emotive experience for everyone concerned. The following reflects the mixed messages that we heard in that for most people the process works well, but that is not always the case. It is important that we learn from and improve the process for a timely diagnosis and intervention.

2.1 What works well

For the majority of people diagnosed with dementia it was the positive act of GPs listening and referring on for diagnostic tests, and referring to the memory service. Overall there were replies that GPs took people seriously and that a diagnosis was a positive outcome as was their attendance at the Memory Service. Two younger people said that initially they were classed as being 'out of county.' Once in Shropshire the service they said that the service they received was very timely and efficient from the GP to Memory Services.

A carer of an older person diagnosed with dementia spoke highly of the services and the support his relative was receiving. One person had care support because they were experiencing falls and was quickly referred on for tests. They were diagnosed as having dementia.

One person who went for a routine health check was referred on and diagnosed with dementia. They were quite satisfied and glad things were spotted in a timely manner.

Providers said that early diagnosis for individuals and for younger people services was working well. A timely diagnosis allowed for timely future planning and to set up Power of Attorney. Some workers identified good practice between their local medical practice and ward rounds with the mental health hospital.

Providers reported that at diagnosis people are provided with medication, assistive technologies and occupational health assessments to assist the newly diagnosed person to remain independent. This is supported further through a follow up from a support worker who can provide relevant information and refer on if required to care and support within the community.

Care co-ordinators where highly valued especially by GPs and because they were based within GP surgeries they have knowledge of the local support available. One carer was very glad that the Alzheimer's Society was very proactive following diagnosis of a loved one. Without this intervention they believe they would not have known what to do.

Carers reported that respite care planning was important to support their wellbeing and to help their loved one to adjust in case of an emergency. The People to People Team was reported by two carers as being a timely intervention and providing positive support.

Providers also said that carers assessments worked well and carers were recommended to attend an education programme about supporting their loved one and themselves on the journey following a dementia diagnosis.

2.2. What is not working well

It was reported that people can be either ignored and sent away, at least initially, or they were diagnosed in an efficient and timely way.

Three people expressed views that going to the GP with concerns about memory, and that their symptoms were ignored or misdiagnosed. A small number commented on a prolonged journey to reaching a diagnosis, or GPs not doing enough sooner. Some commented that after diagnosis there was no support. Some younger people said that their employers and occupational health staff failed to consider dementia as a possible reason for deteriorating health in the workplace, too often focussing on stress and depression.

One carer said that 10 years ago their partner went to see his GP who tested his memory and asked him to name as many animals as he could in one minute. The GP then told him ‘that’s normal’. This carer said that two years later her partner was referred on for tests and scans. Again he was told by his GP that it was not dementia. Eventually her partner was referred for memory problems to the Outreach Nurse, and from then onwards, received very positive support in getting a formal diagnosis. This process took 2 years in total and a lot of persistence by the carer’s partner to get a diagnosis.

For another person with memory difficulties it was their daughter who noticed symptoms initially. They were referred on by their GP for further screening and received a timely diagnosis. After which there was no support. Younger people particularly, said initially their signs and symptoms were misdiagnosed with stress and depression. A carer of a loved one seeking a diagnosis was very perplexed, because it took them five years of appointments before their GP acknowledged there was a problem. By which time the person had deteriorated and was then diagnosed with vascular dementia.

Service providers reported that diagnosis could be ‘hit and miss’ affair. For example, providers said that some GPs actively referred on for tests whilst others were dismissive and negative. Providers said that negative GP comments were such as;

> *“What is the point in early diagnosis?”*

And

> *“increasing diagnosis when there is no money going into treatment and interventions”*

Some providers were critical of the 28 days pathway for diagnosis taking longer, due to the time taken for screening and blood tests, which delayed the times for patients accessing memory services.

Other issues commented on were around a lack of awareness of not understanding the individuals’ needs and a lack of information at diagnosis and post diagnosis. It was also reported at the provider forum that there were ‘non specialists’ doing memory assessments.

There was a wide range of comments from carers post diagnosis. One carer said a nurse came to their home and gave her loved one a diagnosis without her being there with him. There was a mixed opinion on handouts and leaflets post diagnosis. Some carers liked to have handouts and leaflets and would refer back to it as needed. Others said they put the information away in a drawer and felt overpowered by it all. For some it was put in the drawer and they would go back and read it. Some carers did not feel listened to or left out in terms of support and/or care planning. Two carers said that the memory clinic failed to co-ordinate appointments with them for their loved one. One carer was quite upset when a nurse came to visit her partner, when she was not present, and gave them the diagnosis. This was upsetting because at no point was she involved and she felt excluded.

Following diagnosis and medication two people diagnosed with dementia and their carers felt abandoned. One carer wanted a medication dispenser which they said they were not offered at the time and nothing was highlighted about assistive technologies.

2.3 Gaps, opportunities and other comments

Providers emphasised the importance of an early diagnosis as a passport to accessing treatments and support and to enable patients to plan ahead. It was said that although NICE Guidelines encouraged early diagnosis for people in care homes by GPs and the Memory Services there was a gap in joint working protocols and support to enable this to happen. It was noted that there is a worker from the memory service that goes into care homes to diagnose and support.

Some individuals following diagnosis felt left to manage without further discussions or support of any kind. Eventually this left them confused about who or where to turn to if needed. Others said that they thought the carers education training programme was useful but that not many people attended. Many thought that carers fell through the net. It was said on occasions there was no support available to allow a carer to attend this programme because that depended on the availability of a care service.

Recommendations

- GPs training updates about the need for a timely diagnosis, to differentiate differences and symptoms of anxiety, depression and dementia particularly in younger people.
- Proactively encourage early care planning and support.
- Improve joint working between Heath & social Care and the voluntary services.
- Individual needs and expectations must be considered – "see me not my dementia"

Objective 3 Accessing High Quality Care and Support.

A carer wrote a letter of compliment about the care and support the couple had received from Shropshire's Memory Service for Younger People (their loved one is now classed as in the older person age group, and has recently entered a long term care home)

> *"Everything up to now has been very positive and I can only hope that it will continue to be this way. I would like to thank everyone who has made this possible"*

Accessing high quality care and support was the most commented on compared to the other 4 objectives on the Action Plan. Providers' Responses mirrored those of people living with dementia and their carers. All the groups mentioned below were very popular meeting places and sources of information and support.

3.1 What works well

The greatest number of replies was about the popularity of groups. Younger people particularly enjoyed attending groups like Al's Café, Ladies Who Lunch, and The Men's

Group, because they enjoyed being with their peers who had similar interests and who were generally more active than their older counterparts.

The Carer's Group was very popular too: carers could talk to others who have been through or are going through the same experiences as themselves and ask questions. It was repeatedly commented on that shared peer support and learning from each other helped to forge strong and meaningful connections.

The Memory Service For Younger People verbally stated that they felt wholly supported they especially enjoyed attending the various groups that were voluntarily run via the Outreach Nurse.

The Alzheimer's Society run groups such as The Dementia Cafes, Singing for the Brain, and groups run by the Memory Service and Age UK. Carers enjoyed attending groups with their loved ones and also groups just for carers. The same was true for younger people with dementia. The Care & Share Group was popular because both the person with dementia and their carer can attend together whereby activities were shared and /or separate, in the 3 hours provided. Additionally, carers could choose to have 3 hours respite through Care & Share once a month.

A carer wrote:

> *"When we accessed services from the Memory Services they were wonderful and lots of new opportunities came along…"*

Another carer commented that:

> *"The service after diagnosis was very good. Regular visits at home for the first six months. The groups for men, women, carers, Al's Café keep you in touch"*

Groups are valued and seen to be of great benefit. Other support noted, although not specifically for people living with Dementia, were the Good Neighbours Scheme and Dial a Ride.

Providers responses reinforced the findings that befriending services and telephone contact services were working well and various other groups for example, peer support groups for carers and the Care & Share Group, which offers low cost support and respite for the individual and their carer together. Volunteer activity groups with a case co-ordinator worked well too. The Alzheimer's Society support workers and Carer Information and Support Programme (CrISP) and, groups were all working well to support people with dementia and carers.

Service providers said that the Memory Service and Home Treatment Team and the Rapid Assessment Interface & Discharge Team (RAID) were working well too. They said that Dementia Care Plans from GP practices were good because they were printed out and shared with the patient.

Positive comments from carers and people living well with dementia were:

> *"It's fantastic to have a person to talk to over the telephone from Carers RCC. I okay at night. I attended both training events because husband attended a day care centre which freed me up. I can't leave him now unattended".*
>
> *"There is nothing I would change or improve on"*
>
> *"I am well supported by my family and friends and I have helpful neighbours too"*

> *“Nothing can be improved I am living well with dementia”*
>
> *“I think the dementia café is good and my church is dementia friendly too”*

3.2 What is not working well

Providers told us that information sharing could be difficult due to disjointed information systems and poor internet connections. They said the separation of health and social care funding was not working well for them, that there was a high turnover of staff and an increased workload. Providers said there was a lack of support for people without a formal diagnosis, a lack of respite for carers and a lack of community dementia friendly activities. They also told us that some domiciliary care support was not dementia specialised and that there was a lack of Elderly Mentally Ill specialism beds, which can result in people being placed further from home and cause difficulties for carers and families to visit their loved one.

Carers and people with dementia were concerned that regular visits from Community Mental Health Nurses had been reduced, and then reduced further to a telephone call from a team member. We have no available figures as to how often this occurs. The issue of who to contact out of hours was very difficult for carers who said that they felt professionals themselves were not clear how to support and that they were passed onto to different teams for advice and help. Communication was difficult because carers felt that they had difficulty in saying what it was they wanted or explaining difficulties they were experiencing with their loved one. Being pushed to other agencies and having to explain the issues all over again was very stressful.

Another carer who was supported himself by mental health services, said that at first he and his partner were seen every four weeks. However, this quickly was reduced to six weeks, and then six months. For them as a carer and a mental health patient in their own right, they felt very tired, unhappy and unable to challenge this.

> *“Not having regular three week visits from our nurse was upsetting and it took a while for things to be acceptable”*

And from other carers;

> *“Regular contact with the same person would be very acceptable”*

Carers said that they lacked knowledge of what their rights are and of what is available to support them. This issue was raised particularly around carer assessments and respite care. Some carers said they felt abandoned once they were assessed as being ‘self funding’ They lacked confidence and awareness on how to effectively find the care and support they needed. Two carers said that after respite in a care home, their loved ones were wearing continence pads, clothing had gone missing and dentures looked like they had never been cleaned. Both people with dementia and carers were experiencing the dementia journey for the first time. The carers involved were too upset to complain and relatives stepped in to support and raise complaints. This led the carers to lose confidence in future care support and concerns that the care home staff were not adequately understanding of the care and support needs of their loved ones.

A total of six responses said that there was no high quality care. There was definitely a sense that support ‘equals who and what you know’. One carer stated that his partner had five moves before finally finding a care home nearby that matched their loved ones needs.

Another carer remarked that as his partner's disease progressed they were moved to various care homes in different areas too often. There simply was no choice; they had to accept where the care home was.

Carers enjoyed a worker coming to their home and taking their loved one out so that they had a break and there loved enjoyed getting out of the house. For many this has been lost.

3.3 Gaps, opportunities and other comments

Information such as hand outs and leaflets could be given in stages rather than all at once. Carers responses gave mixed opinion on this. Some carers welcomed it others put the information away because they felt overwhelmed by it.

Service providers want better internet connectivity and broadband, and IT systems that are joined up with each other. It would be helpful to carers and people with dementia to have a flow chart of 'who is who' rather than lots of different pieces of assessment paperwork or cards. Carers said they were not confident to access information online and, even if they were, they said they needed recommended guidance on credible sources.

The Passports were very useful pieces of written communication on care planning and the support needs of people living with dementia. Providers would like to see this more widely used. It was suggested by some workers that 'Summary Care Records' (DH Lead) could be utilised more effectively.

There was a lack of awareness of what services and organisations locally offered as support. Providers and carers would like more specialist EMI beds in hospitals and care homes local to where patients /loved ones lived. Providers said they would like to see access improved on the out of hours service. Carers would like to know how better to access support in one place rather than being transferred or asked to phone another agency. Navigating help in a crisis was made even more stressful because of this.

Providers told us that hospital discharges could be improved if there was increased availability to domiciliary home care. And carers told us that discharges would be improved and less wastage incurred if medication needs were assessed with the individual and their carer's needs taken into account.

For others transport was a gap especially if their loved one had to give up driving; this was more problematic for people living in rural areas. People who lived rurally were prepared to travel to groups if transport was available; there is a need to improve transport to attend groups.

It was clear that people with dementia liked to attend support groups that involved mixing with their peers who had similar strengths and active interests. In addition, Men enjoyed Men's Groups and vice versa. Older people and carers enjoyed attending together but would prefer to be in peer groups also. People newly diagnosed with dementia want to keep up with their usual interests and activities in an 'inclusive' way. For example, if they were part of a walking group prior to diagnosis, they wanted the people in the group to be supportive and dementia friendly. Peer groups were enjoyed by all, but are not universally available across Shropshire.

'Personalisation' and 'normalisation' were a desired outcome if people and carers are to enjoy positive outcomes and wellbeing.

Recommendations

- A care advisor / navigator who will know the person with dementia and family to support and guide them through their dementia journey.
- Useful easy to read flow chart of ‘who is who’ and how organisations are connected.
- Continuity of workers to support care choices.
- Establish joint budgets and services in health and social services.
- Provision of specialist dementia training at the appropriate level that will provide positive outcomes and wellbeing to those people who use services including carers.
- Reduce hospital admissions for urinary tract infections.
- Improve hospital discharge times and support.
- Medication on discharge should be dispensed to meet individual and carer needs.

Objective 4 People are able to live well and reduce the risk of crisis

There were a lot of similarities in both the responses from service providers, carers and people living with dementia. Carers and people living with dementia had lots to say about this objective, which was by far the most commented on.

4.1 What works well

Providers said that learning together training programmes such as those run by the Community Council For Shropshire. Libraries training for carers and the CrISP programme were all working well towards positive outcomes for people living with dementia and carers.

When discussing communities, providers said that initiatives such as community hubs, compassionate and resilient communities and community care co-ordinators, respite care, dementia cafes and Diamond Drop Ins all worked well. Organisations identified in the workshops as good support were the Alzheimer’s Society, Age UK, Shropshire Rural Community Council Carers’ Support Service (but it is noted that this is now being delivered by Carers Trust 4 All).

Providers said that Passports worked well for them, when they were in place and up to date. It worked well when carers were registered as a carer, as this identified them as carers and allowed carers to access services. Carers taking time for themselves, the support of family, friends and carer assessments and proactive regular respite were all things that made a positive difference when they worked well.

The majority of positive comments were about people living well due to their own efforts and / or support from family and groups.

17 people in total said they were living well. Two were carers whose loved ones had entered a long term care home. 10 people said they were living well either because they were remaining independent to maintain their usual living routines or they had family support and attended groups.

> *"Personal assistants, Alzheimer's Group, Painting Groups, groups set up by our outreach nurse, Men's Groups, Carer's Groups. These allowed for a semblance of normal life"*

One person living with dementia said that early planning and decision making that includes their involvement in developing a shared Living Plan, that contains everything from carers and contact numbers, as well as what is needed to support them to live well is good. A plan that is meaningful, personalised and individually tailored allows a person with dementia to live well. This plan should also be shared with relevant people and services who are involved in the care.

Carers told us that having a care package for their loved one helped them to live well too. A person with dementia said that support from professionals and meeting people who have dementia helped them feel that they were supported and not alone.

Comments included:

> *"Info pack from several sources was a godsend"*
>
> *"Support from family and professionals help me to remain living at home"*
>
> *"It worked well - support of professionals. Meeting people who also have dementia and not feeling alone with this diagnosis "*

A carer said, that the Rapid Response Service helped them in a crisis over a medication problem:

> *"Once my problem of ensuring twice daily tablets were successfully taken by being provided with a tablet dispenser, things have improved greatly. All staff show a great understanding of how to help and act promptly. Thank you"*

4.2 What is not working well

Comments centred very much around topics of hospital medication, respite and contradicted some of the above responses.

Providers' responses were about a lack of beds, hospital discharge planning, respite care and carers. Care providers said that there are either no acute beds or not enough beds. They reported that patients who were not taking their medications would deteriorate into a crisis. The crisis that ensues makes re-admission more difficult and can lead to inappropriate emergency placements or Mental Health admissions.

> *"Very difficult to navigate [the system] - leads to inappropriate placements and sections"*

Some said that in theory patients can be referred and seen by the service urgently but in practice there are not enough resources.

Providers said that carers don't always know they are a carer and others are not accepting that they are a carer. In both cases this results in them being excluded from receiving a carers' assessment. Providers said identifying carers in a crisis was not working well.

Other areas identified were poor hospital discharge planning, and discharges on a Friday afternoon; when encountered this can lead lack of appropriate support and can become a crisis situation. The 'This is Me' passport is currently not widely available or used, which means that staff involved do not have access to relevant up to date information.

Carers and people living with dementia gave many responses the main topics were of GPs, poor hospital discharge medication issues, respite and feeling alone especially when families have work and their own family commitments. A carer said:

> *"You feel on your own, people don't understand"*
>
> *"Services not knowing who to contact so I could get the right help on a weekend. It became a crisis situation"*
>
> *"What happens if you have no structure? Crisis happens generally when the carer needs more respite - more respite is needed"*
>
> *"Very recent discharge with telephone number. Complicated medically. Terrible service. COCO and Masie very supportive"*

One carer said of their GP that they had arranged a Do Not Attempt Resuscitation without consulting them and that the hospital was not aware of it. Another carer in a crisis situation was not happy with their GP when they rang for support as their loved one appeared ill and was slurring their speech. The carer said,

> *"…I phoned for an ambulance and the paramedics arrived and diagnosed diabetic coma and put up an emergency drip. An hour earlier the GP had assessed the loved one as being "okay"."*

One carer said of their carers assessment,

> *"I feel that if you come over as being a capable carer services back off. My situation became a crisis."*

Another carer said.

> *"People 2 People assessment for carers was not very helpful".*

4.3 Gaps, opportunities and other comments

Care providers said that there was of a lack of transport in some areas of the county, no named social worker, a lack of week end support, that assistive technology at present has patchy access (poor internet connections & getting resource availability known).

Providers suggested that refuge collectors and postal workers could be trained dementia champions and that it is an opportunity to include dementia awareness training and dementia champions in tender documentation to make them contractual obligations

Additionally, it was said that large employers could commission CrISP courses because there is likely to be enough people in caring roles at any given time to run the course.

They said there is a gap in that there are no Admiral Nurses or specialist nurse contacts in Shropshire.

People living with dementia wanted to continue to live their lives as they had before diagnosis and for their communities to be inclusive until such times as they were unable to continue due to progression of the disease. They also enjoy being in groups with other people diagnosed with dementia. Younger people living with dementia said they enjoyed men only or woman only groups.

Carers also enjoyed attending groups; for everyone transport can be problematic. Carers liked to be separate from loved ones to free them up to talk freely or offload feelings without fear of upsetting their loved one. The also enjoyed attending other groups.

A carer said,

> *"My support could be improved by continued support and access to groups"*

Another said,

> *"Planned respite to suit us 3 hours twice a week and every 6 weeks for 1 week. Carers can recharge their batteries and overall care for longer"*

A person with younger person living with dementia said,

> *"Living well needs breaks for carers, dementia friendly communities, updated care/living plan and what action to take in a crisis"*

Recommendations

- Carers need to be empowered to speak up and ask for assessments
- Partnership working across agencies /information sharing needs to be developed to support families
- Continued drive to make communities dementia friendly and aware.
- Inclusion in group and community activities should be encouraged for as long as possible to provide normalisation
- Regular support, including peer support, should be available locally; continuity is also important.
- Recognition of the importance of the caring role
- Timely and adequate respite for carers is required with an emphasis on the preventative aspect to avoid crises
- Clear contacts of who to phone in an emergency or at a week end.
- Robust forward planning
- Promote the continued use of "passports" and have a standard version
- Increase the use of assistive technologies.

Objective 5 Ensure high Quality End Of Life Care

This topic was very sensitive to discuss and we were up against time constraints in the focus groups. Never the less, the people who wanted to contribute did so, whilst others choose to sit this topic out. At the SURPS group we ran out of time and did not cover this objective for this group.

5.1 What works well

Care providers were straight to the point and commented positively on more that worked well than did not. The providers surveyed agreed that there is good legal information and that Age UK scheme "access to a solicitor for older people" was working well. Lasting Power of Attorney was all planned early to prevent costly and emotionally charged situations at the end of life.

They said that in their opinion staff were well trained in End of Life care support and that innovative care was in place between the Severn Hospice, COCO (where this service exists) and the Alzheimer's Society. People had a choice of place of death such as their own home, care home and / or hospice. They said that trained GPs, District Nurses worked well to enable people to die at home if they wish, and some residential homes were very good at end of life care. And that;

> *"Care homes have improved very much and do a good job with low pay"*

Of all the people living with dementia and carers only three people had planned ahead. There comments were as follows;

> *"My wife and I have spoken about our wishes and we know what to do"*
>
> *"I have Power of Attorney for money and health"*

"…I have everything sorted. It's all paid up with dignity. Funeral paid, last wishes etc. Power of Attorney, all done nothing left to do. Last POA for health and finances when father died so it's all in order. Completed Lasting Power of Attorney online" to die at home.

5.2. What is not working well

Care providers comments focussed on lack of workers having a good conversation about end of life care, the individual end of life plans, and workers not being very competent with cultural diversity. There was

> *"a lack of skill in facilliatory end of life conversations with families"*

They said that there is a need for more GPs and District Nurses to be trained in end of life matters, POA were made for finances but people were not aware of health POA. Providers expressed concerns about getting continuing healthcare funding for those considered to be at the end of life stage.

One group of carers talked about their GP raising the subject and one person said that being asked about it was a 'box ticking exercise'.

There was some discussion in one group of carers who said doctors asked about "do not attempt resuscitation" question out of context. The group were confused about this question and why ask now.

Comments from people who have made arrangements said:

> *"Legal things were put into place and were very costly"*
>
> *"My solicitor needed to liaise with GP and hospital (mental Health) to complete a form; this is too expensive. Need to make system smoother and less costly"*

Other individuals talked about the importance of dignity, and fears of being alone. Some said they made POA when first diagnosed, others said that a good time to plan and discuss this is when you are in a good place, and not emotional, they recognised a need and so far had not made firm plans.

5.3 Gaps, opportunities and other comments

The response on this section was limited. Care providers said that we needed specialist end of life care in the community and that too many patients were dying in hospital. They said that there was a lack of access to hospices and a lack of volunteers for the COCO service. They said there needed to be more post-bereavement support.

Other comments said that churches and faith groups have a role as support of individuals and in the community. The cost of private nursing care to support people to die at home needs consideration where people's wishes are to be respected.

Recommendations

- Lack of knowledge about rights must be addressed
- Proactive and sensitive awareness raising for people newly diagnosed with dementia on end of life planning, directives and rights.
- Advice that is timely to raise and to discuss end of life choices and directives.
- A fair and equitable legal advice service and access for all individuals to enable advance planning and to ensure future plans and wishes are actioned.
- For all providers from all sectors to work together to share expertise, knowledge and resources to support people with dementia, carers and neighbourhoods to break down barriers of stigma around end of life care and support.

6 Dissemination event

This event, held in March 2016, presented the findings from the focus groups and the provider event to 44, of whom 9 were people living with dementia and their carers. The audience discussion on the project findings emphasised that:

- Experiences vary across the county
- Accessing services can be a challenge both physically getting there and also knowing what is available.
- Each individual has individual needs
- Needs vary depending on the stage on the dementia journey
- Implications for adult safeguarding need to be taken into account
- The voluntary and community sector has a key role to play
- Respite care is a key issue for both the cared for and particularly the carers; regular "preventative" respite is essential but crisis respite has to be available.

7 Findings from the medical student project

The five final year medical students who were involved in the project were attached to three practices in Shropshire and one in Worcestershire, although Shropshire patients were registered with this practice. There was remarkable agreement between the practices from the interviews of both GPs and Care Co-ordinators. Strengths and weaknesses of dementia care were highlighted and recommendations made. The full report can be accessed here.

There were mixed views of the benefits of early diagnosis. It was thought that the benefits would differ with different patient circumstances. The importance of the knowledge of individual patients and their needs was emphasised. Once a formal diagnosis was made care co-ordinators were really appreciated by the GPs for the work that they do in supporting these patients.

The important role of carers was recognised by all the interviewees. In all the practices carers were coded as being so on their patient records. This could mean a lower threshold for treatment or could trigger respite care. There appeared to be no consistency of approach.

There was, however, a lack of awareness of the Shropshire Dementia Strategy Action Plan amongst the practices and their GPs. This was also true when Healthwatch Shropshire attended the GP locality meetings to raise awareness of this work.

The medical students were fortunate to receive a Dementia Friend session from the Alzheimer's Society which was well received. At their feedback session with the Medical School this was highlighted as a highlight of their 16 week project with Healthwatch Shropshire. The session enabled the students to understand Dementia from the patient perspective. With the ageing population in Shropshire the requirement to be "dementia aware" would seem essential for all medical students.

Recommendations

- Awareness of the Dementia Strategy Action Plan amongst GPs and their practices needs to be increased
- Care co-ordinators are recommended for all GP practices and they should work with others with knowledge about local services to support those living with dementia
- There needs to be a continued drive to reduce the stigma and misconceptions about dementia; education should be provided to the general public and information should be provided through the general practice
- GPs should share their ideas for good practice in dementia care
- All medical students (and other students such as nursing, physiotherapy etc) should have the opportunity to undertake a Dementia Friend training session.

Limitations of the methodology

The engagement undertaken to inform the findings was geographically spread across the county. Existing groups were visited and the numbers involved were manageable with in the time frame and provided a richness of information. However, further engagement is needed with people whose voice is “seldom heard” including people from the nine protected characteristics, those who are isolated, those living in residential and nursing homes and those who are not currently accessing services, for whatever reason.

There was an under-estimate of the time required in the focus groups as people were very willing to share their experiences and their thoughts. Time was an important constraint.

It was agreed that transcription would have been useful at all “events” due to the richness of the information.

Discussion

The project team was humbled by the willingness of the participants to share their experiences and to give their time freely. Despite the limitations outlined above there is a richness in the information provided and confidence in the findings and the recommendations as there was a remarkable consistency in the feedback from the different participating groups: people living with dementia, their carers, the providers and GP practices.

It is worth pointing out the engagement demonstrated that both people's expectations are diverse as are their experiences. The engagement also reinforced that needs change as the "dementia journey" progresses and must be taken into account in considering the provision of services, in the widest sense.

It is clear that for some people the "dementia journey" is good and works well for them and their carers. If the journey starts well it appears that it is more likely to continue well. For others the journey is less good; what works well for one individual does not necessarily work well for someone else. This was also found in the WMADASS survey. This highlights the need to provide individual personalised care and support.

Local models of care and support may also vary across the county. However, what is important is that some key fundamental principles are established in the refreshed action plan but they may be delivered differently in different parts of the county. Shropshire is a rural county but the characteristics vary across the county and one model will not necessarily fit all. However it is important that the key aspects of care (in its broadest sense) are available to all.

During this collaborative project we have been made aware of good practice that is taking place not only locally but across the UK and also looked at other Dementia Strategy Action Plans. It is clear that there is no need to "reinvent the wheel" but that Shropshire should learn from available good practice.

Taking this into account and the complexity of the existing Dementia Strategy Action Plan in Shropshire the final recommendations (below) take the findings and recommendations outlined above and use headings that could be used in a refreshed action plan. This approach will enable the link to be made more easily between this collaborative project and the refreshed action plan. The focus of the refreshed action plan is to address identified need and to deliver improved outcomes for people living with dementia and their carers.

Ownership of the Refreshed Dementia Strategy Action Plan needs to be established by the Health and Wellbeing Board and individual organisations need to be empowered to take on responsibility for the actions with in their scope. A communications and engagement plan will be required.

If the implementation is to be successful progress will need to be monitored and outcomes measured. The working group that has supported this co-production project could be expanded to ensure a wider representation (for example to include the Dementia Action Alliance for Shropshire, the independent sector, general practice) but should remain manageable to ensure constructive discussion and that progress is being made.

The Action Plan also needs to be integrated with other local initiatives taking place across Shropshire such as the Better Care Fund, the Mental Health Partnership and resilient communities. These links are being developed. Representatives of the working group are members of the Health Economy Dementia Steering Group which is an information sharing group and is important for ensuring that everyone knows what is happening across the county.

Awareness of the context in which everyone is working has also been considered in formulating the recommendations and developing the Action Plan. There is not abundance of resources available at any level in terms of service provision whether in the community, a GP practice, the voluntary and community sector, the NHS or in the CCG or local authority. Parity of esteem was noted as a potential issue. The need to postpone access to statutory services and encourage independence for as long as possible is acknowledged and is taken account of in the recommendations. The implications for individuals to take on greater responsibility for their wellbeing are also addressed in the Action Plan. It is crucial that alternative support and information is available and the need to integrate these recommendations with other initiatives such as Community Fit.

It is really important that the outcomes from this collaborative project and the refreshed action plan are shared with the groups that participated in the project, the providers and the GP practices. Further engagement should also take place to ensure that more voices have the opportunity to share their experiences and influence or participate in the implementation.

A key finding from the collaborative project is that people "don't know what they don't know" at the start of their journey so are unable to ask the right questions and this can affect their journey and the care they receive. As a result raising awareness of both the public and professionals is the starting point for our recommendations and the revised action plan.

Recommendations

A "keep it simple" approach is recommended for the refreshed Action Plan in order to identify clear objectives and actions with clear lines of responsibilities and time frames.

The recommendations from the collaborative project are set out below under the priority headings being considered for the refreshed Dementia Strategy Action Plan. The numbers in brackets relate directly to the headings in the refreshed Action Plan. The text in blue shows recommendations that could be considered for early implementation through the Action Plan as they will make an impact quickly or because they have been identified as key issues during this project.

In addition to support the Strategy and Action Plan cross cutting themes were identified:

- It was recognised that there is currently good practice across the county but that it was inconsistent and that these inequalities should be addressed

- Joint working between Heath & social Care and the voluntary and community sector should be encouraged, including establishing joint budgets

- Develop a communications and engagement plan to raise awareness of the action plan and its implementation. Key organisations including Shropshire Clinical Commissioning Group (CCG), Shropshire Council, Shropshire Dementia Action Alliance, the Business Board, Public Health should be involved (8.4.10)

- Further engagement with other groups of people whose voices are seldom heard is needed to raise awareness of services and support and to identify any additional needs

1. Preventing Well

a) Encourage dementia awareness, understanding and reduction of stigma in communities, services, schools and businesses. More openness and encouragement to talk about dementia is needed. (8.1, 8.4.5)

b) Ensure that both professionals and the public are aware of the need to protect vulnerable adults and know how to raise a concern (8.1)

2. Diagnosing Well

a) Include information about the need for a timely diagnosis in GP training updates, and emphasise differences between the symptoms of anxiety, depression and dementia particularly in younger people (8.2)

b) Encourage GP practices to develop Dementia Champions and provide dementia awareness training for all staff in doctors surgeries (8.2)

c) Encourage GP practices to become dementia friendly in terms of the physical environment and attitude of workers (8.2)

d) Encourage sharing ideas for good practice in dementia care by GPs and their practices (8.2)

e) Increase awareness of the Dementia Strategy Action Plan amongst GPs and their practice staff (8.2 and Communication and Engagement Strategy).

f) Widely promote the Dementia Road Map across the county (8.2, 8.4.10)

g) Provide comprehensive information to ensure there is full knowledge about rights (8.2, 8.4.10)

h) Take into account the information needs of individuals and consider when and how information is required (8.2, 8.4.10, 8.4.7)

i) Follow up the initial engagement with GP practices and participate in GP locality meetings to continue to raise awareness of and maintain momentum in the implementation of the refreshed Action Plan (Communication and Engagement Strategy).

3. Living Well

a) Continue the drive to make communities dementia friendly and aware of issues around dementia (8.4.4)

b) Provide specialist dementia training at the appropriate level to ensure positive outcomes and wellbeing for those people who use services including their carers (8.4.6, 8.4.8, 8.7.3)

c) Raise awareness with employers about the impact of dementia to enable support and reasonable adjustments to be made, as young onset dementia is currently an issue but as the workforce ages the incidence of dementia amongst employees could reasonably be expected to increase (8.4.4, 8.4.5)

d) Encourage inclusion in group and community activities for as long as possible to provide normalisation (8.4.4)

e) Care planning must be person centred (8.4.1)

f) Recognise and manage people's expectations of care needs; there needs to be continuity in terms of workers to support care choices (8.4.10)

g) Proactively encourage care planning (8.4.1)

h) Make regular support, including peer support, available locally; continuity is also important (8.4.4, 8.4.5, 8.4.6)

i) Increase the use of assistive technologies to support people for as long as possible in their own homes (8.4.4)
j) Recognise the importance of the caring role; individuals also need to recognise their role as carers. The Memory Services should have a key role in supporting carers (8.4.6)

k) Empower carers to speak up and ask for a needs assessment (8.4.6, 8.4.10)

l) Provide guidance to carers to ensure that they get the most out of their appointments and that the assessments are meaningful (8.4.6)

m) Support and encourage individuals to take more responsibility for ensuring that their own needs are identified e.g. in a GP consultation by preparing questions, writing answers down (8.4.6)

n) Make available a useful easy to read chart of 'who is who' and how organisations are connected, identifying key individuals (with contact details) who are involved in the care plan, with clear contact details for emergencies and week ends(8.4.10)

o) Explore provision of appropriate community support for this younger group of people (8.4.7, 8.4.1) .

p) Involve young people with dementia in taking forward work to implement this strategy (Communication and Engagement Strategy).

4. Supporting Well

a) All medical students (and other students such as nursing, physiotherapy etc) should have the opportunity to undertake a Dementia Friend training session and be aware of the concept of "parity of esteem"

b) Make the Action Plan available on the CCG web site along with other local guidelines, strategies and policies (Communication and Engagement Strategy)

c) Link other web sites such as Shropshire Choices, Shropshire Together and Healthy Shropshire to the Action Plan (Communication and Engagement Strategy)

d) Promote the continued use of "passports" and agree a standard version (8.4.7)

e) Develop partnership working across agencies and information sharing to support families (8.2, 8.4)

f) All GP practices should have Community Care co-ordinators and should work with others with knowledge about local services to support those living with dementia (8.4)

g) Provide every person living with dementia with a 'dementia care advisor' who will know that person and their family be able to support and guide them through their dementia journey; a 'dementia care advisor' could be a Community Care Co-ordinator in the GP practice (8.4)

h) Ensure the 'dementia care advisor' has the knowledge and expertise to provide support and has received Dementia Friend Training; the principle should apply across the county acknowledging that the local solution will determine who the advisor is (8.4.3)

i) Make regular support, including peer support, available locally; continuity is also important (8.4.6)

j) Respite for carers is required with an emphasis on the preventative aspect to avoid a crisis; respite provision is a complex issue and requires further exploration as a priority (8.7.6)

k) Reduce hospital admissions for urinary tract infections, using the Memory Service to raise the profile of this issue particularly with carers (8.7.4, 8.7.3 and 8.4.2, 8.4.9)

l) Improve the quality of hospital discharges including discharge times and support and the provision of medication (8.7.9).

5. Dying Well

a) Encourage proactive and sensitive awareness raising for people newly diagnosed with dementia on end of life planning, directives and rights (8.4.1)

b) Make available a fair and equitable legal advice service with access for all individuals to enable advance planning and to ensure future plans and wishes are actioned (8.4.1)

c) All providers from all sectors to work together to share expertise, knowledge and resources to support people with dementia, carers and neighbourhoods to break down barriers of stigma around end of life care and support (8.8)

Conclusion

The working group has met to consider the draft report and it is being used to inform the refreshed Dementia Strategy Action Plan for Shropshire, which will include timeframes and identify those responsible for the actions required.

In conclusion the project showed that there is good care available for the people of Shropshire who are living with dementia and their carers – the challenge is to make this high quality care available to everyone affected by Dementia, independent of where they live. Information is powerful and a good start will be to improve awareness of information and services available so that people are able to ask the right questions, make informed choices and influence the care that they receive.