

*Living Well With Dementia in Aberdeen City:
Creating Communities That Care*

A Scoping Project carried out by Professor John Swinton, University of Aberdeen.

Section One:

The background to the project

The project emerged from a series of conversations between Tom Cowan and Professor John Swinton around what it might mean to live well with dementia within Aberdeen City and whether there are things that could be done differently in order to enhance and develop the admirable work that currently goes on within the city. John Swinton nursed within the area of mental health for 16 years. He was also a mental health chaplain at the Royal Cornhill Hospital in Aberdeen. He is currently a professor at the University of Aberdeen. Prof Swinton has researched extensively into the nature of dementia with a particular focus on quality of life issues. Both agreed that there was some excellent work going on within Aberdeen City and that the current Dementia Action Plan continues to be successful in drawing out key issues regarding effective care and good practice, something that is reflected in the recent progress update¹. Nevertheless, with the vision of the health and social care partnership developing as it is rolled out across the city there remains a need for ongoing creative and aspirational thinking that could provide some key pointers for future development and the fulfilment of the Plan's goals. Tom Cowan commissioned John Swinton to do a short scoping project designed to scope out some new future proof and person centred possibilities for developing dementia care within Aberdeen City.

A scoping project

It is important to be clear that *the work reflected in this report is not formal service review*. Service review is designed to identify potential service delivery improvements with the intention of improving an organisation's efficiency, effectiveness and sustainability. Such a review would involve in-depth exploration of the various dementia services within the city with a view to examining what works, what does not work and what requires to be done in order or ensure future sustainability. Such a project would require a much larger piece of work than this current project.

This report reflects the outcome of a scoping project that was designed to present a snapshot of the ways in which a variety of stakeholders feel things are going within the city and to offer a series of possibilities for enhancing person centred care, drawn from a variety of

¹ 'Dementia Action Plan makes solid start.' Aberdeen Health and Social Care Partnership. 2016. m <http://www.aberdeencityhscp.scot/en/progress/news/dementia-action-plan-update/>

contexts that respond to the issues raised by participants and which have the potential to contribute positively to:

- a) The realisation of the goals of the Aberdeen City Health and Social Care Partnership Strategic Plan 2016-19².
- b) Meeting the stated goals of the Dementia Strategy for Aberdeen City, 2014-2024³.

The project was intended as a scoping project in lieu of the possibility of a larger piece of work emerging in response to the findings of this report. This report should therefore be read as potentially foundational for a wider project aimed at further developing bespoke person-centred services for people with dementia and also working towards the broader goal of Aberdeen City becoming a dementia friendly city whose citizens are dementia friendly people.

The shape of the project

The two questions that were key throughout this project were:

1. *What does it mean for people with dementia and their supporters, to live life to the full within Aberdeen city?*
2. *What is required in order to enable them to do so?*

Following on from a consultation with the North East Research Ethics Committee it was decided that this project should *not* be classified as research⁴. It was felt that it was best to categorise it as service development: an exploration of certain aspects of current practice and service provision with a view to encouraging creative development for the future. Whilst the terms “interview” and “focus groups” will be used, the qualitative information presented in this report is best understood as emerging from a series of individual and group *conversations* rather than formal research interviews. A conversation is an informal talk within which news and ideas are exchanged. The openness of a conversation was deemed more appropriate for an information gathering scoping project such as this.

²Aberdeen City Health and Social Care Partnership Strategic Plan 2016-19 <http://ihub.scot/media/1110/aberdeen-city.pdf>

³Dementia Strategy for Aberdeen City, 2014-2024:
<http://www.aberdeencityhscp.scot/contentassets/5e7b18acbc7748069a3ffd02053c1bcf/dementia-action-plan-update-july-2016.pdf>

⁴ The judgement was made in accordance with the NRES guidance paper *Defining Research*:
<http://www.hra.nhs.uk/documents/2016/06/defining-research.pdf>

The project had two aspects:

1. A series of conversations with people living with dementia and those offering care and support (both lay and professional). These conversations revolved around current experiences of services, key issues that have arisen from that experience and aspirations as to what might be required for further development.
2. In response to these conversations a number of potential models drawn from a variety of contexts and focused on creative change were developed and presented specifically as they might relate to the work of dementia care within Aberdeen city.

As mentioned, the follow-on project from this study will look at the implementation of the findings of this report. At that stage the intention is that the project will go out to tender.

The original intention for phase 1 was to work with 6 Focus Groups comprising of:

1. Families and carers
2. People with dementia
3. GPs
4. Mental health professionals working in the area of dementia.
5. Care providers working in day facilities and longer term care provision.
6. Voluntary and third sector organisations

It was however clear that some people with dementia were inhibited by the formal Focus Group forum. Consequently, alongside of the formal focus groups, Prof Swinton carried out an additional four conversations with people living independently with dementia. It proved logistically difficult to bring together two of the groups - GPs and care home providers - so the information was gathered through personal conversations. Alongside of the focus groups a series of conversations with health and social care personnel was carried out. *The total number of people involved in the study that underpins this report was 75.*

Dementia in Aberdeen City: Setting the context

It is an obvious fact that the numbers of people living with dementia is increasing at a significant rate nationally and internationally. Alzheimer's Disease International estimated that in 2015, 46.8 million people worldwide were living with some form of dementia. This number will almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050⁵. Across Scotland in the region of 90,000 people have dementia. Alzheimer Scotland estimate that 1 in 9 carers across the country are looking after someone with dementia. Within Aberdeen City Alzheimer's Scotland estimates that 3,372 people live with dementia (1558 males and 2631 females)⁶. Around 7,760 people aged 50 and over are providing unpaid care within Aberdeen City, including 3.5 % of people aged 85 and over. It is clear that the care of people living with dementia and those offering them care and support is highly significant for the work and strategy of Aberdeen City's Health and Social Care Partnership (ACHSCP).

It is however, *very* important that we properly frame the increasing numbers of people living with dementia within the city. *The increase in dementia should not be perceived primarily as a set of problems to be solved.* We should always be cautious, careful and thoughtful about the kind of language we use in relation to people living with dementia. The way we talk about a condition will determine the ways in which we perceive it and in turn how we relate to those individuals that bear the name of that condition. If at the level of management or clinical practice, dementia is perceived as "simply another *problem* to be solved," then providing care for people with dementia and those who support them, becomes just another burdensome task that needs to be paid for out of an ever shrinking budget.

It will be more fruitful to think about dementia care in terms of *citizenship*: enabling all of the citizens of Aberdeen City to live well. So, the question is not: "how can we deal with the problem of dementia?" Problems and challenges will arise, but they should not and must not define our attitude towards dementia care and people living with dementia. The more important and appropriate question is: *How can we enable all of the citizens of Aberdeen city to live well, including those living with dementia.* Speaking properly about dementia is fundamental in ensuring the kind of excellence in dementia service provision that fulfils ACHSCP's desire to provide care that:

- Takes account of the particular needs of different recipients.

⁵ Alzheimer's Disease International, *Dementia Statistics*; <https://www.alz.co.uk/research/statistics>

⁶ Alzheimer's Scotland 'Statistics: Estimated number of people with dementia in Scotland. 2016:' http://www.alzscot.org/assets/0002/0373/2016_Webpage_Stats.pdf

- Takes account of the particular needs of recipients from different parts of the area in which the service is being provided.
- Takes account of the particular characteristics and circumstances of different service users.
- Respects the rights of service users.
- Takes account of the dignity of service users.
- Takes account of the participation by service users in the community in which service users live⁷.

People are not problems even if certain issues may be challenging.

Dementia as an enduring illness

Before we move into the main issues surrounding the report, one more point of clarification is necessary. Too often people with dementia are treated as having something which is hopeless, progressive and terminal. There is some debate as to whether dementia should be classified as a terminal condition or a chronic illness⁸. This is not the place to enter into the complexities of this discussion. Nevertheless, the debate raises an important issue. There is an advantage in thinking about dementia as an enduring illness rather than a terminal condition. To name a condition ‘terminal,’ provides a story that speaks of inevitable progressive decline with an ever looming focus on impending death. Whilst there may be some logic to this way of thinking, such a story easily occludes the fact that if people are provided with the conditions and the resources to cope creatively with their situation, people with dementia can lead positive and fulfilling lives that are not determined by the fear of impending death and worsening disablement. Decline may be in some senses inevitable (as it is for everyone), but it is not the only story that we can tell about the experience of dementia. Thinking in terms of enduring illness, in the same way as we now use the term ‘enduring’ rather than ‘chronic’ within mental health care might be conducive to creative care and management which focuses on living well and coping effectively⁹.

⁷ Aberdeen City Health and Social Care Partnership Strategic Plan 2016-19. <http://ihub.scot/media/1110/aberdeen-city.pdf>

⁸ IRIS 01. ‘Thinking long-term: the future of dementia in the UK: http://dementia.stir.ac.uk/system/files/filedepot/24/01976_dsd_c_iris_thinking_long_term_paper_13a.pdf

⁹ Mental Welfare Commission for Scotland (August 2016) *Living with severe and enduring mental illness in Scotland*. Edinburgh: Mental Welfare Commission.

Section Two:

Aberdeen’s Health and Social Care Partnership: An Integrated, Person Centred Approach to Dementia Care

This report was commissioned by and speaks into Aberdeen City’s Health and Social Care Partnership. The intention of ACHSCP is to bring together the diversity of health and social care providers within the city (voluntary and professional), and to develop an integrated system of person centred care which will effectively meet the complex care needs of the citizens of Aberdeen in a way that mobilises the natural resources and assets of the city¹⁰. The vision is to create a “caring partnership working together with our city communities to enable people to achieve fulfilling and healthier lives and wellbeing¹¹.” In order to achieve this vision it is necessary to develop integrated services that place individuals, families and communities at the centre of thinking and practice.

Person Centred Community Care

Because community and person centred approaches are so central to the ethos of ACHSCP and for the purposes of this report, it is important to be clear what these things are and what they are not. ACHSCP assumes an *assets based approach*. Assets based approaches focus on the factors that protect and enhance people’s health and well-being and in so doing seek to improve quality of life, by drawing attention to that within a community which improves self-esteem and the ability to cope. It is important to note that in this way of thinking, *community is not simply understood as a geographical area. Rather it is a series of resources (people and relational networks) and potential resources that, if accessed effectively, can participate positively in the development of the health and wellbeing of the Citizens of Aberdeen city.* Community, community building and community mobilisation are thus central to the goals and current and future aspirations of ACHSCP.

Understanding community in this way is important if we are properly to understand the meaning and nature of person centred care. *Person centred dementia care does not simply mean looking at the individual. It means looking at the individual within the context of their community.* Reflecting on the difference between ‘patient centred care’ and ‘person centred

¹⁰ Aberdeen Health and Social Care Partnership: <http://www.aberdeencityhscp.scot/>

¹¹ ACHSP Partnership Vision: <http://www.aberdeencityhscp.scot/en/why-integrate/>

care will help draw out the importance of this point. There is much literature around the importance of ‘patient centred care.’ Patient centred care seeks to replace physician centred systems with one which revolves around the patient. The idea is that the patient should be involved in every aspect of their care. Rather than being the object of care they become the subject of their own care. As we will see later in the report, this idea is important within a healthcare context. However, simply focusing on the individual is not what makes person centred care person centred.

A ‘patient’ can be understood apart from their community and looked at without any necessary reference to their families, friends, hopes, dreams, likes, dislikes etc. “Dementia patients” have their identity primarily defined by their condition. “People living with dementia” on the other hand, can only be understood as they are recognised as part of a complicated matrix of relationships within which they live, find their identity and seek happiness and fulfilment. Genuinely person centred dementia care does not simply look at the individual, it always looks at the individual-in-their-community. *To be a person is always to be a person-in-relationship.* Community is central to personhood.

Dementia thus always belongs to a community. Certainly it manifests itself in unique individuals, but it always affects and indeed always belongs to a community of people. The welfare of individuals is dependent on the welfare, wellbeing and good will of their communities. Person Centred Dementia Care therefore requires the formation of communities (professional and lay), who care; both the immediate community of family and friends, and the wider community within which a person is trying to live their lives well. ACHSP’s focus on community, community development and community empowerment is consequently vital for the authenticity of its claim to be seeking to develop person centred care¹². Thinking about dementia in terms of community is central to what follows.

¹² AHSCP expresses the desire to encourage, nurture and intentionally facilitate the development of communities that can actively participate in the care and support of people with dementia and their families. This is in line with the Scottish Governments emphasis on co-production: “delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours.” Elke Loeffler, Gerry Power, Tony Bovaird and Frankie Hine (eds) *Co-production of Health and Wellbeing in Scotland*. Scottish Co-production Network

Section Three:

Voices from Experience and Practice **Key Issues highlighted through focus groups and conversations** **with health and social care personnel.**

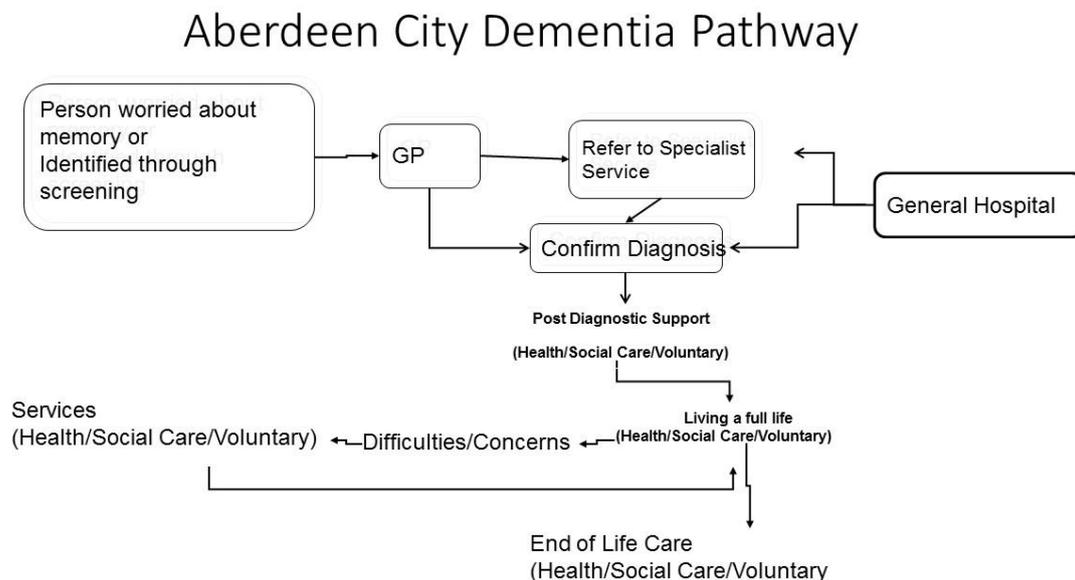
The person should always be at the heart of everything, even if that takes a little longer

(Sheila who lives with dementia)

In this section of the report we will examine some of the issues and perspectives that arose from the various conversations that took place between John Swinton and the various stakeholders who participated in the project. The material is organised around key prominent issues related specifically to the remit of this study as it has been outlined above.

The Aberdeen City Care Pathway

The basic care pathway within Aberdeen City seems to run something like the diagram below¹³:



¹³ Rosi Sweeten (2012) Integrated Care Pathway for Dementia – 2012.’ Aberdeen: NHS Grampian.

We might layer it in this way:

Level 1: Medicine and Psychology.

Level 2: Health and social care services in tandem with the voluntary sector.

Level 3: Care Homes.

This structure is clearly overly simplistic. Level one also includes family, friends, and health and social care professionals, all of whom are deeply involved. Likewise, GPs may well be involved in all three levels. Nevertheless, this basic structure is indicative of a particular dynamic and division of responsibility and helps give a feel for how the pathway runs.

The study participants pointed out three issues that were problematic:

1. The idea of a care pathway is primarily a way of organising thinking around the experiences that people living with dementia have and highlighting how services might best be structured to meet people's needs at the various stages. It might be a helpful guide, but its trajectory is never fixed. People come into it and move out of it in various ways and at various times. Stages 1, 2 & 3 are not necessarily a forward progression. So for example, for some, stage one is bypassed for a quite considerable amount of time. The Living Well café s in Aberdeen city have people who have never had a diagnosis and who are not in contact with the services, but are clearly trying to manage how best to live well with serious memory impairments. Stage 2 is to some extent often dependant on the GP's awareness of and ability to effectively signpost a person into stage 2. Likewise dying well, which often occurs in stage 3, requires adequate input from those agencies and people responsible for stages 1 & 2. The care pathway often moves backwards and forwards and sometimes even sideward, rather than rumbling progressively onwards. The care pathway is therefore not so much a series of formal stages as it is a series of connected moments in a person's journey with dementia. If those responsible for each stage do not see the connectedness between the stages problems occur.
2. One significant danger of failing to see the complex and necessary interconnectedness of the care pathway is that particular parts of the care pathway implicitly or explicitly become valued more highly than others. So, for example, some care home personnel

felt their work was not valued as much as other aspects along the care pathway. They felt that sometimes their work was seen as “the end of the line;” as one person put it:

“everyone seems to see care homes as the place where people go when everything else has ended or failed.”

Some of the care home providers felt that their homes were sometimes considered the endpoint of a sad downwards process rather than places where people could continue to live their lives as fully as possible:

“It’s good to keep people in the community for as long as possible as long as they have good quality of life. ... But that doesn’t mean that people can’t have good quality of life in a care home ... at least in principle.”

The danger with thinking in terms of care pathways in the way that has been outlined above, is that there is a kind of built in downwards trajectory. This downwards movement within the pathway is exacerbated if we frame dementia as a terminal illness wherein care homes become perceived as primarily “waiting rooms for dying people” rather than places where people can find new opportunities for living well. Likewise some felt that the way in which care homes were commissioned meant that they were required to provide services that offered good quality of care, but that quality for life issues were legislatively optional. The suggestion (implicit or explicit) that quality of life within care homes is legislatively optional is indicative of a particular perception of the role of the care home.

3. It was suggested that whilst we might want to keep the idea of care pathways as an organising concept for professionals and for policy development, the idea of *dementia as a journey* might be closer to the reality of people’s lives:

“It’s more of a journey than a clear path. Journeys are a bit messier than pathways!”

It was very clear from people’s responses in this study that they felt their experiences of dementia were closer to a journey than a pathway. A pathway is a course of action aimed at achieving a specified result. A journey is the act of traveling from one place to another. One is instrumental and focused on presumed clinical outcomes; the other is flexible, person centred and open to surprises. A journey is something one embarks upon willingly or otherwise as one moves from one place to another. Along the way you meet people and encounter situations, some of which are helpful some that are not. Each encounter changes the direction of your journey. Some encounters change the

meaning of your journey. In practice, the journey of people living with dementia and their supporters is often closer to the winter journey of a displaced refugee than an organised summer hike. The destination, like the road before you, can be pretty unclear. *The key thing about a journey is that you are always heading towards somewhere and something; not nowhere and nothing. Destination matters.* Thinking of dementia as a journey keeps people's eyes on the necessity to have in mind precisely what kind of destination one would desire the person living with dementia to reach. According to the structure of the city's dementia care pathway the endpoint of the journey seem to be death, whereas for *all* of the people who took part in this study, the endpoint of the journey was to live well, even as one nears death. This report suggests that we are best to think of dementia as a journey that has a recognised (but not fully fixed) pathway of progression¹⁴. Thinking of the care pathway in this way enables us to think positively about each aspect of the journey.

Quality of Care and Quality of Life

One issue that arose which has a good deal of practical significance at a number of levels is the sometimes uneasy tension between quality of care and quality of life. As might be expected, all participants desired that people living with dementia should receive good quality of care. However, the relationship between quality of care and quality of life proved to be complicated. As mentioned, it is possible to have a service which provides excellent quality of care whilst at the same time paying little or even no attention to a person's quality of life. A simple illustration will help make this point.

Imagine that you are a person with dementia lying in a care home bed. A carer comes in and begins to offer provide you with good basic care. She seems to be competent, able and well informed. Then, for whatever reason, you begin to realise that she is taking care *of* you, but doesn't care *for* you as a person. In fact she doesn't really care for anything other than the formal clinical manifestations of your illness. She is very competent at what she is doing, but her primary motive is efficiency and ensuring legal adherence to particular policies, rules and regulations. The quality of care you have is excellent, but you feel like an object; an endpoint

¹⁴ NHS Education for Scotland. 'Dementia Skilled – Improving Practice: Learning Resource: http://www.nes.scot.nhs.uk/media/857092/dementia_skilled_final.pdf

for someone else's' work. Worse, you may be clean, but you are certainly not fulfilled. Your care has done nothing to enhance your quality of life.

Process driven care

A concern highlighted by a number of participants was that policy or process driven care could bring about good quality of care, but sometimes did very little in terms of improving people's quality of life. If you have a flexible, outcome driven system wherein people are allowed creativity and flexibility as to how the outcomes are achieved, it is much more likely that a balance between quality of care and quality of life will be attained. The implications of this suggestion came to the fore in this study in some of the discussions around Self Directed Support (SDS). An expressed concern was that SDS was not being used creatively:

“There are still a lot of challenges around this and some social workers have actually told some families that it would be too hard for them to be employers. We need more good, positive stories around SDS.”

SDS aims to “help people get the right support ... by giving them more choice and control over how their support needs are met and by whom.” So the intended outcome of SDS is choice and control. The idea is that people's needs are no longer determined by the constrictions of the system. Instead, the system is determined by people's needs. However, some participants suggested that people are not being encouraged to “think outside the box.” If people's needs are bound by assumptions about what is or is not possible within current care provision systems, then they may receive good quality for care, but they will not achieve the quality of life outcomes that SDS strives to deliver, that is: *choice and control*.

Quality of care is of course fundamentally important. There are certain immovable foundations for good dementia care in Aberdeen city that have to be securely in place before quality of life can become a reasonable, sustainable possibility: adequate nutrition, well designed housing, appropriate levels of respite care, access to services (including transport), and so forth. However, attention to quality of care without due attention to issues around quality of life leads to services which are adequate, but neither creative nor life enhancing; places where people live safely, but don't necessarily live well. Person centred community care understood in the way it was described earlier in this report requires people to think beyond the obvious and holds in tension the need for quality of care (the things that make life possible and bearable) and quality of life (the things that make life worth living).

Repositioning Care homes

Shifting our thinking from pathway to journey and from fixed processes to desired outcomes begins to address a significant concern that merged from the conversations with care home providers and others, and that is the sometimes negative ways in which care homes are perceived. There is a real danger that if we implicitly or explicitly perceive the care pathway as a downwards movement into the care home, the creative possibilities of care homes will be lost or overshadowed by the self-fulfilling prophecy of negative expectations. If people are to live well with dementia, each dimension of the journey needs to be perceived as an opportunity for people to flourish. This means that care homes need to be thoughtful, creative, *life* oriented and appropriately funded. That is not to downplay the fact that many people will die in care home facilities. It is however to emphasise that living well and dying well are part of the same dynamic process. Enabling people to live well at each point in the journey and respecting and understanding the work of those who accompany people in various different ways is the key to a truly integrated person centred care pathway.

Issues around diagnosis

We were relieved to get a diagnosis. It made us a bit more understanding of what was going on. We were a bit more patient with him.

(Bridgette, a family carer)

For carers and people with dementia the ongoing role of the GP was considered fundamentally important. The GP was seen as the gateway both to diagnosis and to post diagnostic services. People spoke highly of GPs and most people had had positive encounters both at the stage of diagnosis and in terms of post diagnostic support. There seems to be four aspects of people's encounters (people with dementia, carers and support workers) with their GPs that they wanted to bring to the fore:

1. *Recognising the power of diagnosis.* Diagnosis was perceived as both a relief and a challenge. At one level it was a relief insofar as the speculation that people had often been engaging in now had resolution. The diagnosis helped explain certain things and enabled people better to cope better with the situation. It was a challenge insofar as dementia is a highly stigmatised diagnosis that is not always welcomed by its recipients:

“I didn’t feel I was able to tell the people at my work ... I wanted to keep my job ... I wanted to keep my friends ...”

Adjusting to the new identity that comes with the diagnosis of dementia is not always easy. Diagnosis was clearly perceived as being as much a social as a medical experience.

2. *Early diagnosis.* It was acknowledged by some GPs that there was a “hidden burden of undiagnosed dementia”. One GP described this as “the iceberg phenomenon.” Whilst many people do receive an appropriate diagnosis, many do not. Some participants had had to wait for quite some time before they or their loved one received a diagnosis. This could be quite distressing as it is often obvious to the family, but not necessarily obvious to the GP. The GP’s job within this area is inevitably difficult and at times a little fraught. At one level, not everyone who presents with memory issues has dementia. One GP noted that:

“One of the problems is that most people who present to us themselves with concern about their memory are actually anxious rather than dementing [sic]: in other words memories are not being laid down because of problems with attention. The people with Alzheimer’s tend to be brought by others, and I think most of those cases are investigated promptly once they appear in our consulting room.”

This raises another issue. People bring their loved one to the GP surgery knowing that something is not quite right. However, as one GP put it:

“It can be pretty difficult, particularly when the person themselves might not want to acknowledge that they have a difficulty. It’s a difficult tension between respecting the autonomy of the person with dementia and alienating family members by downplaying the importance of their stories.”

The issue of early diagnosis was a difficult one. On the one hand relatives clearly wanted an early diagnosis which from their point of view was helpful at a number of levels. On the other hand, as one GP put it:

“Since no truly effective treatments exist, early diagnosis is often just extra time living with bad news. Where the memory problems cause functional difficulties, or there is a need to liberate funding or services the diagnosis is usually expedited. Many older people seem reluctant to have a diagnosis of dementia, and as long as they retain capacity for health decisions we cannot and should not force referral on them (this can frustrate relatives!)”

Other GPs saw things a little differently:

“Diagnostic labelling doesn’t faze me. If it enables people to access particular services that is a good thing. I tend to think of dementia not so much as a disease; rather it is a natural process that requires acceptance and a compassionate pragmatic response. In the end, you don’t need a doctor to tell you have dementia. People usually have a pretty good awareness anyway. What a diagnosis does is it unlocks services. My sense is that there may be a problem here and that looking at ways of unlinking diagnosis from service access might be something worth considering.”

3. *Communication with relatives.* Some relatives did indicate a sense of alienation insofar as they felt that sometimes their perspective wasn’t really heard. Often their loved one would deny what they clearly knew to be the case. However, this serves to highlight a real dilemma for GPs:

“We can of course listen to relatives, but can only discuss the patient’s case with them if we have the patient’s explicit consent, or if we judge that the patient lacks capacity and there is a power of attorney in place.”

GPs are quite correctly ethically bound to focus on the individual with possible symptoms of dementia, but at the same time that can cause distress for the relative who lives out a different story from the one being told in the consultation conversation.

4. *Continuity of care.* Because the GP is so important to the process of entry into and movement through the dementia journey, continuity of relationship was flagged up as very important. Those who seemed to benefit most from GP input had had the same doctor for many years. He or she understood the personal complexities of people’s situation and was able to give a continuing informed perspective as things move on:

“If you can see one doctor who knows you we are treated as a couple. But if you just phone up and get a strange doctor that is much less helpful. You need a designated doctor.”

Seeing the same GP regularly was one way of coordinating someone’s care. However, from the perspective of GP practice such continuity is inevitably very context dependant:

“[it is] much easier in small practices which is why their levels of patient satisfaction are much higher. The problem is getting bigger with a move towards more part time working and bigger practices.”

Coordination and continuity of service delivery.

I'm not looking for sympathy. I'm looking for coordination!

(Jenny who lives with dementia)

This issue of continuity of care over time was deemed to be important both for the receivers and the deliverer's of dementia related services. This emerged on three levels.

1. *Continuity and communication across services.* A frequent general comment from service users was that they felt the services they received were of a high standard, but that sometimes they were rather uncoordinated, particularly if someone has to move from one sector into another (e.g. from GP surgery to hospital). Some people felt that they had to tell the same story numerous times to different professionals. Likewise, there was sometimes a lack of coordination between departments dealing with people living with dementia. So for example, on one occasion a participant, who has dementia and is a primary carer for her husband who also has dementia, found herself having *five* appointments for her husband in the same day! As she put it: "I got tired hearing my own story!"

2. *Continuity of personnel.* A lack of continuity was also an issue in relation to home care, where people could sometimes have several carers coming in during the day and even more over the period of a week or a month. The one thing that the people wanted was continuity of care and continuity of the people delivering that care:

"It's confusing when you don't know who is coming in the next day or even on the same day!"

Care staff were clearly aware of this as an issue, but were limited in how they could respond by restricted capacity.

3. *Transitions and interdisciplinary awareness.* Connected with the previous point are issues around transitioning from one part of the health and social care system to another. When people are in those parts of the service which have a specific focus on dementia things tend to run quite smoothly. So, when for example, people encounter GPs,

psychiatrists, psychologists, community psychiatric nurses, social workers, specialist voluntary and third sector entities, they tend to have quite positive experiences that include sympathy, empathy and understanding. It is when they deviate from the formal dementia services that people can encounter significant difficulties. One participant's father who had dementia broke his leg and ended up in an orthopaedic unit. When he moved from dementia care into general services, things became quite difficult. Staff had no real awareness of dementia and how they should react to the situation, which led to awkwardness, poor communication around key issues and tense relationships.

Some people expressed concern around the way certain medical decisions had been made. One woman whose husband had dementia and prostate cancer was told that he couldn't be operated on because he wouldn't be able to cope with post-operative care.

"I think it's because, mainly, people with dementia are older and they are all going to die pretty soon anyway. My husband couldn't get an operation for his prostate because ... Oh well, he wouldn't really understand what was involved in terms of after care. They thought that if he got the operation after care it would be down to whoever was in the hospital to deal with him and maybe there wasn't anyone who was an expert in dementia. There is a great degree of ageism, especially ageism and fears and negative assumptions around dementia."

The problem here was not so much the poor delivery of difficult news, but the fact that the issue was premised not on deep knowledge of the person-as-person, but on negative assumptions about the nature of dementia and the capabilities of people with dementia. The issue was not malicious intent, but rather negate presumptions and a lack of understanding and awareness. If there is inadequate awareness of dementia across systems and between disciplines, effective quality of care becomes difficult and person centred life enhancing care becomes if not impossible certainly not obvious.

Post post diagnostic support.

At the moment the Scottish government has legislated that people receive a year's post diagnostic support. This task is carried out by Alzheimer's Scotland dementia link workers¹⁵.

¹⁵ Dementia Link Workers should not to be confused with Community Links Practitioners/Often called Links workers. Dementia Link Workers are part of the National Dementia Plan and must be provided under legislation. However, the Community Links Workers (Links Workers) concept comes from 'At the Deep End' surgeries across Scotland which have practices in the most deprived postcodes in Scotland: <http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend/>

The consensus of participants was that this was an excellent service which functions well as long as there is adequate capacity. Nonetheless, important as this service is, people pointed out two important issues in relation to post diagnostic care:

1. Many of the issues that arise for people living with dementia do not necessarily arise during the first year following diagnosis. Some people felt that they didn't really need much support at this stage. It was later as things changed that the need for support and information often became more acute:

“You don't necessarily need a Link Worker in the first year. In our case we didn't. I mean we're two and a half years down the line and we are really beginning to encounter different problems and issues. ... The link workers were excellent in terms of support, knowledge and information, but two years on that information may be out of date. So where do we go then?”

2. Dementia link workers can only provide a certain level of information before they have to refer a person on to another part of the system. If that part of the system is not well informed around dementia issues, problems can occur:

“Link workers are wonderful sources of knowledge. But when it comes to certain issues such as respite care, a link worker can only refer on, which is where the communicational breakdown can come in. So they can signpost you and then you might hit brick walls.”

It is important to note that these issues are *not* in any sense a criticism of dementia link workers whom people felt did excellent work. They are general issues that relate to broader issues around post diagnostic support.

One stop shop signposting

The consensus among carers and people with dementia was that there should be some kind of one stop signposting system that people could access in order to get relevant information at any stage of their dementia journey:

“What we need is a one stop shop where somebody can lay out for you: this is how it works, these are the options, this is who you need to talk to and to try and move you through because at the moment it feels like wading through treacle and you're grabbing a bit here and a bit there. Putting that together is key. ... you need to know what is available and what is the route potentially that you might follow.”

One care home provider put the issue slightly differently:

“It's not so much that we need a single place to go. We need to have contact points across the city and across organisations”.

What people seemed to be saying in different ways was that joined up information was hard to find after the first year following diagnosis. What they wanted was some kind of one stop shop (or a series of informational access points across the city) where it was easy to access both information and advice. People seemed keen to stress that this shouldn't be web based as, a) not everyone can access the internet and b) personal advice from people is better - both psychologically and practically - than generic advice from computers.

Caring for carers.

Carers don't choose to become carers: it just happens and they have to get on with it; if they did not do it, who would and what would happen to the person they care for?

(David who cares for his wife who is living with dementia)

It was very clear from the various conversations that caring for people living with dementia requires a community of people working together towards a common goal. Carers and support workers very often formed the heart of that community. At one level, person centred care means placing the person with dementia at the centre of conversations around care and support. However, as was pointed out earlier in the report, a person is not a lone figure who can be understood apart from the relationships that makes them who they are and holds them in that identity. People living with dementia (like all of us), can only be properly understood in terms of their relationships with other people. This is one of the things that makes loneliness and isolation so painful and destructive of well-being: *if we need others in order to flourish and we have no one, how can we live well?* Carers and supporters are central to the process of ensuring that people living with dementia can live well. Sometimes they are the only community people have.

There is clearly a significant financial, social, health and relational burden on carers, although many and perhaps most would not conceive of their caring tasks in such terms. *Effectively caring for carers is central to caring for people living with dementia.* The carers participating in this study highlighted two main areas of concern that they felt impacted upon their well-being and consequently the well-being of the people they offered care and support to. One concern was structural, the other relational:

1. Respite Care
2. Being listened to

Respite care

The issue of respite care (long term and short term) was considered to be of fundamental importance. The general problem highlighted in relation to respite care was its lack of availability within the city, particularly in relation to unplanned or/and emergency respite care:

“I asked for respite care for a week only to be told that the council has run out of money and can’t provide it. I offered to pay for it but even then I was told it could be in Huntly, or it could be in Stonehaven and I don’t have transport. And his washing will not be done while he is there either!”

People felt respite care was a priority in terms of sustaining wellbeing and improving quality of life for all involved. Both Rosewell (longer term respite) and Forest Grove (day care) were highlighted - by both carers and professionals - as providing high quality services that offered an excellent standard of care which had a deeply positive impact on people’s quality of life:

“My mother was in Forest Grove and the care she received there was wonderful. The staff were great; people always had such interesting things to do.”

People expressed a desire for more availability of respite care, particularly for short term breaks and for very short term breaks. An example of very short term breaks would be something like the Alzheimer’s Society mindfulness sessions which are designed to enable carers to cope with stress and anxiety. These sessions have a measurably positive impact. However, as one carer put it:

“Even if I wanted to, how am I supposed to find space in my life to get to these sessions when I have my husband on my shoulder all the time? How could I get away?”

Even an hours respite can be important.

Being listened to.

One of the things that came across strongly was that carers often felt disempowered by their situation and sometimes by the systems of care provision that they encountered. It was clear that in terms of their emotional health, people wanted above all else to be listened to. Being listened to meant being taken seriously in conversations around issues of care and support, but it also seemed to refer to simply having the feeling of “being heard:”

“I know there are lots of things that just can’t be changed ... but ... I still think about them ... I don’t know what to do with it all ...”

That people sometimes feel they are not listened to seems slightly ironic bearing in mind that one of the problems people highlighted was having to tell their story multiple times. The issue seems to be *the feeling of not being heard*. As one carer put it:

“We need you to provide safe places for people to have conversations regardless of where they are on their journey, about things that matter, topics such as spirituality, end of life, dreams passions and contributions.”

Managing emotions

*When I was diagnosed with dementia, I knew I'd got it. I'd known for about two years.
But when you come home you are in pieces.*

(Rita who lives with dementia)

Effectively managing emotions was something that was important for people living with dementia and those seeking to offer care and support. The journey into dementia is difficult and taxing for all concerned:

“It is really important to support the whole family, because such a diagnosis can destroy relationships when people are left isolated and in emotional turmoil.”

Some felt that people needed some kind of formal counselling, particularly following their initial diagnosis when their lives took such a difficult turn:

“Counselling needs to be arranged quickly, to deal with crisis and stop people having longer term issues possibly around mental health.”

Not everyone desired counselling, but for those who did, availability was limited, particularly for people living with dementia:

“Counselling is crucial but almost non-existent, for many people affected by dementia.”

The general consensus amongst participants was that there were certain crisis points along the dementia journey where certain forms of psychological intervention were deemed to be helpful. Such interventions included:

- *A buddy system*: “Match up newly diagnosed people with a buddy, someone who wants to help someone via what they have themselves experienced. This is far more powerful sometimes than inexperienced paid people.” “Get people to speak to others who have been through the same experience. Lived experience is so helpful.”
- *Coaching*: spending time with someone with expertise in effective care-giving practices for people diagnosed with dementia and one that recognises and gives

considerable attention to the needs of the caregiver. “As a carer I found coaching really helpful. It just helped me to think about things a wee bit differently.”

Finding meaning, purpose and hope

Don't think of us as stupid people. We need education and things that will bring our minds alive! If you can open a new world that's what we need. If you're stuck at home there is nothing. You feel hemmed in ... the four walls closing in on you; and it makes your mind go slower.

(David who is living with dementia)

Finding positive meaning in life was recognised by all as central to the process of living well. There are many negative stories surrounding dementia; stories that can be deeply destructive for people's wellbeing and sense of positive identity. All of the conversation partners who took part in this study recognised the need to construct different, more positive stories about dementia; stories that included the deep desire that people have to find meaning, purpose and hope even in the midst of difficult times. When asked what he most wanted from life, one gentleman whose dementia was quite advanced simply said: “I would like to be able to say I am David McCarthy!” David's dream was not complicated. In the midst of his growing forgetfulness, he wanted to find ways in which he could sustain his sense of identity and hold on to his feelings of positive self-worth.

People feared boredom:

“When you're stuck at home you're watching television ... it's just boring!”

People living with dementia were very keen for it to be known that they wanted things to do not just any old thing, but things that matched their abilities and more than that, helped them to develop new skills.

“I want to learn a language! I want to use computers for as long as I can. ... I've even started doing maths in my own head. To *learn something*.”

People didn't want to just be “busy,” i.e., doing things simply for the sake of doing things. They wanted to be engaged in things that were interesting, stimulating and challenging.

Transport

One issue that was raised in relation to finding meaningful occupation (by occupation I mean 'positive, life enhancing things to do' rather than necessarily paid employment), and accessing services was the issue of transport. In order to access meaningful activities, a person has to get to the venue which means that they need transport. However, as one person pointed out:

“Transport is a major problem in the city and beyond. Most people don't drive, particularly people living on their own.”

The consensus was that the city had a general lack of capacity in relation to community transport:

“People who are able to book transport (and relatives) find that there is just not enough capacity to meet the need that is out there. We have had numerous patients dropped off ... with either no collection planned or collection planned for hours later due to lack of capacity.”

Also, the booking system can be difficult to negotiate for people with dementia:

“Many people are not able to do this for themselves. People are required to book a week in advance which can be problematic and they cannot book a block of journeys so have to remember to keep booking week on week for any group that they attend regularly.”

Issues around stigma and negative images were clearly very important for people with dementia and indeed in different ways for all of the conversation partners in this study:

“Councils need to get rid of the shuffling speechless 'people-with-dementia' image.”

Sensitising people to the issues surrounding dementia is not of course an easy task:

“Although First Bus have reassured us that their drivers have training re dementia, many people I meet feel that lack of empathy from some drivers is an issue. I don't think this is specific to dementia but relates to disability in general.”

This of course is not necessarily the bus drivers fault:

“Dementia is a hidden disease and only the most perceptive driver will recognise the signs, especially in the 15-30 seconds that they see a passenger before they get on/off the bus. A client who suddenly forgets where they are going or how to get there has no protection within the public transport system.”

Finding activities that encourage meaning, purpose and hope are perceived as very important. How best to create dementia friendly transport networks which allow adequate access to services seems to be essential.

Conclusion

The various conversations that comprise this section of the report have offered some important insights into how people are perceiving dementia care within the city and some of the ways in which those living with dementia are being enabled or dis-abled in their quest to live well. We can sum up the main issues thus:

Key issues emerging from the conversations.

- *The care pathway as a communal journey*
 - Living well at each point in the journey
 - Developing a more positive understanding of care homes
- *Issues around diagnosis*
- *Coordination and continuity of service delivery.*
 - Continuity and communication across services
 - Continuity of personnel
- *Transitions and interdisciplinary awareness*
- *Post post diagnostic support*
 - Signposting: Need for a one stop shop
 - Managing emotions
 - Counselling
 - Buddy system
 - Coaching
 - Listening
- *Caring for carers*
 - Respite care
 - Being listened to
- *Changing attitudes*
 - Creating spaces for friendship development
 - Education of all citizens
- *Finding meaning and purpose*
 - Concerns for people with advanced dementia, particularly those with small or no social circles
- *Transport*
 - Public transport
 - Transport to venues and appointments

With these things in mind we will now move on to explore some possible approaches that have the potential to respond to the issues raised in the conversations and in so doing creatively contribute to ACHSCP's goal of providing integrated health and social care, and Aberdeen city's intention to become a dementia friendly city where *all* of its citizens can live well.

Section Three: *Possibilities for Transformation*

The models of care and community development outlined in the following section of the report offer potential responses to the issues raised in the conversations with people living with dementia, carers, support workers, health and social care personnel and voluntary workers. The initiatives are intended to speak into the stated intentions of the Aberdeen City's Dementia Action Plan and Aberdeen City's Health and Social Care Partnership aspiration to provide services which are:

*Caring
Person Centred
Empowering
Enabling
Cooperative*

Coordination and continuity of service delivery

Too often people in our country experience failures of care. Not because health and care professionals lack skill or compassion. Not because of money. But because health and care services are uncoordinated, sometimes uncommunicative, and centred around what suits organisations and structures, rather than what helps people lead good lives. If we want to deliver care which meets the needs of the patient, if we truly want person-centred care, if we truly want to protect our NHS for the future, new coordinated ways of working are the only answer.

Norman Lamb, [former] Care Minister

In order for ACHSCP to achieve its goals, all involved need to think of their own work in relation to the broader Web of Caring that runs across Aberdeen City. The city council, social work, medicine, nursing, midwifery, the third sector, families, friends and people living with dementia will have to find ways of intentionally coming together to work as parts of the same network working towards shared goals. It was noted earlier that the coordination of services across disciplines was a significant issue for the participants in this study. A major task for ACHSCP is how to bring about a constructive sense of cohesion amongst and between the various professions involved in ACHSCP. Two approaches designed to help resolve

communicational tensions within health and social care partnerships and to bring about cohesive integrative thinking are:

1. Schwartz Rounds
2. The Esther Network

Schwartz Rounds

Schwartz Rounds are an evidence-based forum for staff from all backgrounds to come together to talk about the emotional and social challenges that emerge from their day to day caring experiences. They are interdisciplinary meetings designed specifically to improve staff well-being and improve coherence and understanding across disciplinary boundaries. Schwartz rounds are demonstrably linked with care that is compassionate, high quality and person focused. The aim is to offer staff a safe environment in which to share their stories from their various practices and provide support for one another. The rounds are based on the American system of 'Grand Rounds.' Importantly Schwartz Rounds differ from Grand Rounds in their focus on the non-clinical aspects of care via a multi-professional meeting. Although developed within a medical context, this approach has clear implications for Aberdeen's health and social care partnership.

The rounds run once a month for an hour with a buffet lunch provided. Three or four people tell a short story about their experience of caring for a particular person or their involvement in a specific situation. Presentations last for three or four minutes each and then the rest of the room is invited to participate in the conversation. Speakers talk about the issues, how the situation made them feel, and the nature of the challenges that the situation raised. The Rounds are non-hierarchical, presenting short stories from all aspects of health and social care: porters, voluntary workers, doctors, social workers, nurses, cleaners and so forth. There is a facilitator who in a medical context might be a senior nurse or a doctor. In the context of ACHSCP the facilitation could be the responsibility of a senior figure from either health or social care. Schwartz Rounds prefer the involvement of senior figures within the organisation in the organising and running the sessions, as this gives the impression that the organisation is taking the Rounds seriously. The meeting is very much focused on staff well-being and sharing information and experience across disciplines. Only professionals participate in this forum and the presentation and discussion are confidential. Through this process people come to realise not only what others are *doing*, but how others are *feeling* about what they are doing.

Schwartz Rounds have been shown to be beneficial at a number of levels both personal and organisational:

Benefits for staff

- Encourages compassion.
- Increases empathy and understanding.
- Provides a forum for hearing and validating the concerns of staff¹⁶.
- Decreases stress,
- Decreases isolation
- Leads to greater understanding and appreciation of colleagues roles and contributions
- Helps people feel more supported in their work
- Leads to people feeling more able to provide compassionate care.

The more Rounds an individual attends, the greater the benefit¹⁷.

Benefit for team working

- Encourages networking.
- Strengthens multi-disciplinary working

Anecdotally, nursing staff, physios, all staff really, say they have a greater sympathy for doctors, who seem less cold and hard. And doctors have greater respect for the rest of the team as you appreciate what they do and what they are having to take home with them¹⁸.

It restores faith that you are working with colleagues who can share. There is a lot of angst and low morale in the health service, but this shows there is heart here and we want to do the best for patients. It is quite uplifting¹⁹.

Benefits to hospital/ social care culture

- A less hierarchical environment

Knowing that whatever grade you are you can contribute. All share the same values. I can always contribute if I want. There is always hierarchy in a hospital but in a room like that you are all carers in a caring environment. Your opinion is listened to.

- A culture of openness

...in the context of mid-Staffs, staff are expressing things and the Rounds are a sign that it is safe to speak. It is all very well to say we have an open culture, but this demonstrates that value.

¹⁶ Joanna Goodrich, June 2011. 'Schwartz Center Rounds: Evaluation of the UK Pilots. London: The King's Fund. P. 6.

¹⁷ 'Schwartz Center Rounds: Evaluation of the UK Pilots. P. 3.

¹⁸ 'Schwartz Center Rounds: Evaluation of the UK Pilots. P. 6.

¹⁹ 'Schwartz Center Rounds: Evaluation of the UK Pilots. P. 6.

Schwartz Rounds help an organisation meet its strategic vision in a way that is not focused on targets.

Schwartz rounds have been tried, tested and evaluated in the United States and within the United Kingdom. The evaluation by the King's fund found that Schwartz Rounds:

- Successfully transferred to England.
- Are firmly established and ongoing, with support from the top of the organisations.
- Have demonstrated a need.
- Are greatly valued by the staff who participate (Rounds were given a mean rating of excellent/exceptional by 70 per cent of all participants)²⁰.

Implications for Aberdeen's Health and Social Care Partnership

Schwartz Rounds are a low cost intervention that has been shown to have significant inter-personal and organisational benefits. One of the issues ACHSCP is facing is how it can enable people across the disciplines to find a sense of coherence and fit. There are [anecdotal] indications that staff morale is low in certain areas and that developing ways of sustaining vision, drive, passion and hope may be of primary concern. Schwartz Rounds offers an approach through which these issues can be addressed in a way that makes the term 'partnership' more coherent in the eyes of those working towards its achievement. A healthy workforce leads to health bringing care. A workforce that recognises the value of the other parts of ACHSCP lays down a foundation for overcoming some of the communicational and interdisciplinary difficulties raised in the conversations reflected in relation to dementia in the previous section of this report.

Recommendations

That AHSCP consider piloting the idea of Schwartz Rounds as a way of increasing well-being and morale among staff and working towards the resolution of some of the communicational and cross disciplinary issues highlighted in the previous section. Schwartz rounds are not specific to the area of dementia, but their implications for dealing with some of the communicational and status issues raised in the previous conversations is apparent.

²⁰ 'Schwartz Centre Rounds: Evaluation of the UK Pilots. P. 1.

The Esther Network

“Joined-up, or integrated, services are still the exception, rather than the norm. Dementia care and support is still too focused around structures and systems, rather than the individual needs of the person and their carer. We recognise the importance of spreading best practice of integrated dementia care and support, as well as being a continuing priority across health, social care and wider local government.”

(Prime Minister’s Challenge on Dementia: Year Two update.)

Integrated dementia care that is truly person centred needs to be oriented towards values and outcomes rather than driven by processes, structures and policies. A genuinely person centred system of dementia care does not try to squeeze people into what is already there, but rather allows the person and their needs, desires, and expectations to shape and form the type of care that is delivered and the kinds of goals that are considered desirable. One way of beginning to do this is by personalising the care process. One highly innovative way in which this has been done comes to us via the Swedish healthcare system and the work that has been done around The Esther Network. The Esther Network is part of the healthcare system in Jönköping, Sweden, and is widely recognised as a highly significant innovation in patient-centred care. The Esther Network is a system of care delivery that seeks to provide ‘joined up’ health and social care by focusing on the person/patient as a human being as opposed to a set of outcomes.

The central figure in the Esther Network is an elderly woman named Esther. Esther lived alone. One morning she developed breathing difficulties. She contacted her daughter who didn’t know what to do. Esther then sought medical advice. She was first seen by a district nurse who then referred her to her GP. The GP then referred her to hospital via an ambulance. She was admitted to emergency care where she had to tell her story to various healthcare professionals. Esther had a five hour wait and saw a total of 36 different people, having to retell her story at each point along the way. This was in the midst of her breathing problems. Not surprisingly Esther became confused and could quite easily have been assumed to have dementia. Eventually a doctor admitted her and her treatment began. The Esther Network is an approach to service provision that seeks to avoid the issues that Esther encountered and to ensure that people’s pathways/journeys through the health and social care system is smooth, coherent and that each step is informed by the previous step.

Central to the Esther approach is the constant reminder that Esther is a human being, hence the use of the term Esther rather than patient/service user/client etc. All decisions made

about Esther begins with reflection on what is best for Esther rather than what is best for the system:

1. What does Esther need?
2. What's does Esther want?
3. What is important to Esther when she is not well?
4. What does Esther need when she leaves this hospital?
5. Which providers must cooperate to meet Esther's needs?

The network begins by appointing healthcare and social care workers to examine and assess services not simply according to policy standards but through the eyes of the person who is moving through the system. The evaluation is thus done in collaboration with an elderly person. “Elderly people, with experience of using the healthcare system, have been recruited to provide insights into how the healthcare system works. Often referred to as ‘Esther’s’, they have become valuable partners in shaping services.” The approach is supported by ‘Esther Coaches,’ who are trained members of staff from across the disciplines who have a determination and a passion to ensure that Esther’s experience of health and social care is positive, smooth and coherent. These coaches work in the community and in hospitals, their task being to ensure that the ideas of the Esther Network are embed throughout the system. There are Esther meetings every 6 weeks and there is always an Esther in the room. Thus care systems are developed *with* rather than simply *for* elderly people. “Mutuality is a key value of the network – the vision focuses people to think ‘how best can we work together to do what is best for Esther?’ This supports a culture shift towards an integrated approach that recognises ‘your problem is my problem.’”

The overall intention is to create a shared narrative amongst the various agencies within the system. This development of a shared narrative has been identified by the King’s Fund as one of the high impact interventions needed to make integrated care happen at scale and pace²¹. Other benefits include more efficient and improved prescription and medication routines, increased patient and staff satisfaction, greatly reduced waiting times, more effective treatment and reduced costs, increase in person centred thinking, developing a sense of having

²¹ Chris Ham and Nicola Walsh. (2013) ‘Making integrated care happen at scale and pace.’ London: The King’s Fund.

a shared single vision; enabling all personnel to participate and working towards improvement in partnership.

Implications for AHSCP

The Esther Network as a general approach has potential in terms of facilitating a smooth process for people with a variety of conditions including dementia, through the city's health and social care system. NHS Lothian for example, have used this idea to personalise children's health issues (Sophie), alcohol and mental health problems (Callum), care of elderly people with complex health needs (Hannah) and frail elderly people (Scott). By designing and managing a process of patient and provider engagement around these conditions they have been able to map people's care needs and come to agreements as to how they can be met effectively and efficiently. This approach opens up new possibilities for ACHSCP to develop systems for providing person centred dementia care that are able effectively to deal with some of the difficult issues of movement through the pathways described in the previous section²².

[.]

Recommendation

ACHSCP should consider looking into the viability and applicability of the concept of the Esther Network (either in full or in part), for the integrative work of the Partnership. Its emphasis on person centred care, joined up services and the centrality of co-production indicates that there is at a minimum, a good deal to be learned from the ethos and practice of this model of care delivery. Thinking around the Esther Network may be particularly relevant in relation to the plans to introduce The Buurtzorg model of care which has a not dissimilar ethos²³.

²² During conversations with Jönköping in Sweden, the program coordinator of the Esther Network indicated that there was already an initiative around the Esther Network within Aberdeen City. However, the author of this report has not been able to find any information supporting this suggestion

²³ Buurtzorg is a unique district nursing system which has garnered international acclaim for being entirely nurse-led and cost effective. Royal College of Nursing (2016) 'RCN Policy and International Department Policy Briefing 02/15.August 2015 (Updated April 2016).' This model is currently being considered as an aspect of ACHSCP's developing care approach.

Care Provision: Respite Care

As has been highlighted, the issue of respite care was seen to be of great importance for the people who participated in this study, both for carers and for people living with dementia. The consensus was that respite care is significantly underfunded. Figures show that Aberdeen City are spending less on respite than other areas of Scotland²⁴. For example, Aberdeen City and Aberdeenshire have similar sized populations, but the respite figures are double in the Shire. In 2014-2015 the number of weeks of respite care provided within the city was 3930 as opposed to 6180 weeks provided in Aberdeenshire²⁵. Importantly, people felt that respite care needs to be meaningful and positive for the person with dementia as well as the carer. In other words, respite care needs to be viewed as a significant aspect of a person's quality of life rather than simply a matter of care (and often emergency care) management. What is required is a broad range of flexible respite options – residential, nursing, day care, home based. People also need good information about the respite that is available and what they are entitled to. Here a number of possibilities will be offered:

1. Care homes as respite providers
2. Assurance of security around current services.
3. Shared Lives Scheme.
4. The development of community houses across the city.
5. Effectively utilising church buildings.
6. Possibilities for shared respite, i.e., respite that people do together.
7. More creative use of Self Directed Support.

Care homes and respite care.

A complementary way of getting at the issue of respite care and particularly issues around the difficult transition from home care to full time residency in a care home is via some creative thinking around current usage of care home facilities. Something that was expressed by a number of participants in this study was the desire for respite care that prepared people for full time care. The suggestion was that care homes be used as places of respite, the idea being that this could over time enable people to have a gradual/seamless transition into permanent care.

²⁴ *Respite Care in Scotland 2015: An official statistics publication for Scotland.* The Scottish Government.

²⁵ *Respite Care in Scotland 2015: An official statistics publication for Scotland.* The Scottish Government.

For example one participant's spouse started going to Rosewell 3 years ago, initially twice a year. As time has gone on their time there has increased to almost every month. The person involved loves going there, the staff know him and he knows them. However, Rosewell is purely for respite and at some stage a permanent care home will need to be found. So there will be a good deal of discontinuity for the individual in their transition from home care to full time residential care. One study participant expressed her feelings on this in this way:

“How good it would be if, as his needs changed, as well as my ability to care for him, the balance of his time in care/at home changed accordingly. The system, as it stands, lends itself to crisis and trauma for both the dementia sufferer and the carer and it's cruel. I know from my own thoughts and speaking to lots of other carers the decision of when to “put” their much loved person into full time care weighs heavy and most often they carry on far too long. Often when I'm at carers meetings I look around at the tired stressed faces. It's remarkable to meet the same carers after they've been “set free” from the massive burden and see the change.”

Exploring ways of ensuring continuity of care and continuity of place for individuals as they move on in their dementia journey would seem to be of great importance for carers and for those who are cared for. This does happen elsewhere with people going in to care homes for regular respite with a view to them going there permanently in the future.

The problem of course within the current set up would be that carers can't book planned respite with care homes as the care home tends to have vacancies on an ad hoc basis at short notice (obviously because a room only becomes vacant usually when someone dies) which makes it very difficult for carers to use it for planned breaks. The issue would be whether each care home could keep a room or two free for respite use which people can pre-book. How viable that is financially from the Care Home or Council's point of view is a question that would need to be explored.

Recommendation

ACHSCP considers exploring ways in which care homes can be creatively utilised for respite in ways that can enable and facilitate the difficult transition from home to residential care. Managing this transition in the long and the short term will inevitably be life enhancing for people living with dementia and those offering care and support.

Security and confidence in current respite care provision

One thing that was very clear from this study was that people very much valued, appreciated and thought highly of current respite provision. Both Forest Grove and Rosewell were considered to be excellent facilities by carers, people with dementia and health and social care professionals. There is clearly a need for more services, but these services function to a high standard. However, there was an insecurity about future funding and what the overall plans were in terms of long term planning. This creates an unnecessary anxiety for organisations that provide a key service.

Recommendation

That ACHSCP seeks to reassure current respite care providers as to future funding and offer a clear indication of their intentions for their short and long term futures.

Shared Lives Scheme

Shared Lives is a national scheme that provides an alternative to home care and care homes for adults. “Shared Lives arrangements offer people an opportunity to be supported within an ordinary household or family. Supporting someone within your own home and sharing your family life with them is very different from working in or managing a residential care home. Shared Lives carers do not work shifts or have regular time off but they choose when they wish to offer support or how much time they wish to give, it is their choice. They do not employ staff to provide care to the person placed with them. They balance the needs and wishes of everybody in the household and maintain their own personal life while having responsibility for the person placed with them.

Shared Lives carers are self-employed are not paid by the hour and do not work to a fixed schedule²⁶. This service is used by around 15,000 people in the UK. “A Shared Lives carer and someone who needs support get to know each other and, if they both feel that they will be able to form a long-term bond, they share family and community life. This can mean that the individual becomes a regular daytime or overnight visitor to the Shared Lives carer's

²⁶ Sue Mahony, Team Leader Shared Lives/Adult Placement Scheme. Aberdeenshire Council: <http://www.aberdeenshire.gov.uk/social-care-and-health/community-care/living-independently/shared-lives-scheme>

household. Individuals and families are fully trained and are matched with people looking for a break.”

Shared Lives runs effectively in Aberdeenshire and some provisional conversations have gone on between the Shire and Aberdeen City around this although nothing concrete has been developed thus far²⁷. This concept feeds into ACHSCP’s desire to encourage co-production, mobilise communities to care create situations where meaningful relational networks can become a possibility for people living with dementia.

There is also a Homeshare aspect (Shared Lives Plus) which has been very successful in Australia. Here the dynamic is slightly different. The person who requires care and support shares their home with another person (a student for example) The person invited to stay with the individual does not pay rent and in return commits to a number of hours per week to help support the person in their own home (shopping, gardening, walking chatting etc.). This aspect of Shared Lives will be discussed further below.

Recommendations

This scheme in both of its forms has a good deal of potential to add to the creative respite strategies that the city and ACHSCP are seeking to develop. The recommendation here is that ACHSCP enters into conversation with Shared Lives organisation and the Shire around the possibility of developing a similar scheme within the city. We will return to the issue of Homecare and what a scheme like this could look like later in the report²⁸.

Shared respite

The idea of shared respite simply means that, rather than a person being taken out of their own environment and away from their partner or friends, they share respite together. The Living Well Cafés run in conjunction with the council and local churches would be a good example of this. A frequent comment coming from people using these cafés is: “we haven't done

²⁷ Aberdeenshire Council. ‘Shared Lives scheme’ <http://www.aberdeenshire.gov.uk/social-care-and-health/community-care/living-independently/shared-lives-scheme>

²⁸ The contact person with the Shire is: Sue Mahony, Team Leader Shared Lives/Adult Placement scheme www.aberdeenshire.gov.uk/sharedlives

anything together for years!” Living Well cafés seem to work well in bringing about this kind of short time shared respite.

Community Houses: Tsudoi-ba Sakura-chan

One innovative idea that has the potential for transferability into Aberdeen city is the Japanese innovation known as ‘Tsudoi-ba, Sakura-chan or ‘open house.’ This idea relates to providing an open house within a local community which is hosted by local people aimed at providing day respite and accompaniment for people living with dementia, their carers and supporters. The open house offers lunch and a drop in facility where people can simply drop in for a chat. The facility also offers a 24 hour help line specifically for carers. The Sakura-chan is run completely by volunteers. Importantly, in its original context, the local council in Japan came to the decision that there would be relatively few constraints in terms of overly-protective risk assessments or unhelpful bureaucracy. The volunteers were given responsibility to design and deliver the activities of the facility without being overly hindered by unnecessary rules and regulations. Another example of allowing outcomes to drive processes.

Suzu-no-ya

Suzu-no-ya is another example of the open house concept. Like the ‘Sakura-chan’ initiative, ‘Suzu-no-ya is run on a peer-support and voluntary basis. The house is open for meals and drop in activities along with a 24 hour helpline for carers²⁹. It also offers guidance on preparation for pre and post bereavement counselling. However, there is one thing that Suzu-no-ya offers that is quite unique. Once a week the house has an open day/open house which runs from 9am to 5pm. Here they invite local elderly people, particularly those living alone, to come and join their community. In this way the open house attempts to become a catalyst for creating community for people in the neighbourhood who may have few other opportunities to participate in meaningful community relationships.

As well as offering friendship community and hospitality, Suzu-no-ya functions as a mode of brief respite. During mealtimes, carers move to the upstairs part of the house where they can enjoy some peace and peer support. For some, Suzu-no-ya has come to function as a place for day respite. Suzu-no-ya is deeply person-centred. This manifests itself in small things such as allowing people to eat at the pace they want to eat³⁰. Because there are no normalised

²⁹ This could be linked in with Alzheimer’s Scotland’s current dementia hotline: http://www.alzscot.org/services_and_support/dementia_helpline

³⁰ Note on HammondCare and eating

timescales within the open house, people do not have to meet particular deadlines within the day to complete particular tasks. If someone takes an hour to eat their meal, that is considered fine. Why? Because, rather than being seen as a series of deadlines to be achieved, time is considered to be an asset to be enjoyed. Gifting people time is seen as central to the nature of the type of community that such houses seek to develop. Importantly, Suzu-no-ya is perceived as a ‘professional free zone,’ which serves to emphasise that those participating in the open house are “normal.” Rather than being perceived as clients or patients, they are encouraged to think of themselves primarily as friends. So, whilst there may be therapeutic dimensions to Suzu-no-ya, its primary function is to destigmatise dementia, encourage friendship and provide a sense of belonging which serves to de-medicalise the condition and open it out to become the responsibility of the community.

The idea here would be to have a network of houses across the city that help to seed friendships and draw out community concern and involvement around dementia issues.

Utilising Church Buildings

One set of community resources that are often significantly underused are church buildings. In principle, it would be possible to use appropriate church buildings (with good access and adequate facilities) to run along the lines of community houses. These would differ from the current Living Well Cafés in that they would be full day services (even if only for one day per week), that provide social support, advice and other pastoral services such as counselling, listening (see below) or other appropriate services. The 24 hour hotline could be linked in with the current Alzheimer’s Scotland cares hotline. Again, the idea would be to have a network of groups spread out across the city that help to “seed friendships” and draw community concern and involvement with dementia issues.

Coffee shop communities: FRIENDS Aberdeen

An initiative similar to the Living well café s that currently runs within the city and which has the potential similarly to facilitate short term and joint respite is the FRIENDS network for people living eight mental health challengers. FRIENDS is a coffee shop community that meets regularly in a local coffee shop within the city. The intention of the community is to offer friendship and support. Each letter of the title FRIENDS has a particular meaning: Friendship, Recovery, Interaction, Enjoyment, Network and Discussion. FRIENDS

was set up six years ago by Kathy Hood and Theresa Nicol as a response to this gap in people's lives.

FRIENDS has thirty members, who meet twice weekly in the Oak café at St Marks Church, Aberdeen on Thursdays and at Debenhams' café on Mondays. All members are in recovery from various mental health issues. The main aim of the gathering is the nurturing of friendship. FRIENDS have eight volunteers, two of whom are mental health nurses and one who is a social worker. All are volunteers. They have a steering group consisting of a social worker, a local government councillor, a minister, Rev Duncan Eddie, and a care manager who is a qualified social worker. The steering group meet up with the volunteers two or three times per year in the meeting room of John Lewis's store. The organisation currently finds its own funding from various sources, which pays for regular outings to places of interest.

FRIENDS is a good example of what we might describe as 'coffee shop communities,' that is, small, informal friendship oriented intentional communities that are specifically designed to create spaces where relationships and community can become real possibilities. This is a positive instance of a low cost, community led initiative that has a positive impact on the lives of its participants. Development of an approach like this could compliment the work and intentions of the Living Well café s and also draw in local businesses in ways that are educative and facilitating of dementia friendly commerce.

Coffee shop communities, if coordinated and funded effectively, could act to:

1. Increase the possibilities for meaningful friendships for people with dementia and their carers.
2. Open up opportunities for local businesses to contribute to the dementia friendly atmosphere within the city.
3. Contribute to the need for respite, in this case joint respite.

Implications for Aberdeen city

Creating communities that care is central to achieving the aspirations of ACHSCP. The two models outlined above – open house and café shop communities - are specifically designed to create communities of friendship and care. Approaches such as Sakura-chan and Suzu-no-ya have the potential to be re-contextualised within Aberdeen city. It would require creative usage of current housing stock, or/and the effective usage of church buildings, but the actual running of the open house could be done with minimal cost.

Recommendations

1. In line with its key aspirations to create communities that care and take responsibility for caring, ACHSCP should consider the idea of creating community based facilities along the lines of Sakura-chan and Suzu-no-ya in key areas across the city. Rather than naming them ‘open houses,’ it might be better to name them as ‘Welcoming Communities,’ or ‘Communities of Belonging,’ the primary goal being to create communities of friendship that are open to a broad range of people living with dementia. The intention would be to create spaces for informal, shared respite and friendship development and to encourage community participation and awareness around issues of dementia through invitations for local people to participate and accept the hospitality of the open houses.
2. ACHSCP should consider the idea of creating a network of coffee shop communities across the city. This is a simple, low cost idea that not only creates spaces for meaningful friendships and peer support, but also mobilises local businesses to get involved in dementia issues.

Creative use of Self Directed Support

As mentioned previously, the issue of whether or not self-directed support was being used as creatively as it might be was something that concerned some participants. The issues highlighted were as follows:

1. There was a concern that people weren’t “thinking outside of the box” when it came to the creative use of SDS and that there was a danger that people were not being given adequate choices. Some had the impression that not all professionals were as aware as they might be of the complexities of the process which could lead to people being tempted to go with option 3: “The Council will decide how much money can be spent on your support. You ask the Council to choose and arrange the support that it thinks is right for you.”
2. People felt that there may be a need for local authorities to be less risk averse and to explore more fully the possibilities of providing broader choice and enhancing personal choice and responsibility.

3. Some felt that options 1 & 2 held a good deal of life enhancing potential and seemed keen to explore ways in which they might be developed more fully:
 - a. Option 1: The Council will decide how much money can be spent on your support and you take this money and arrange your own support
 - b. Option 2: The Council will decide how much money can be spent on your support – you choose how your support is provided and the Council arranges this for you.

Implications for Aberdeen City

This issue is not strictly within the remit of this report. However, effectively using SDS has a good deal of potential to improve the wellbeing of people living with dementia and their families and to speak into some of the issues raised in the report, participants viewed on this are pertinent. This combined with the fact that there seem to be some moves afoot to take local councils to court for not using SDS appropriately would indicate that it is something that ACHSCP should be (and are) seriously reflecting on. Moray council³¹ and SPAEN³² (The Scottish Personal Assistant Employers Network) have done some interesting and creative work around this area, particularly with regard to developing option 2. Likewise locally iconnect³³ in Aberdeen City are working through these issues. There is no formal recommendation on this point. However, I would strongly urge ACHSCP to look at how best to develop this useful resource, not simply for fear of legal consequences, but because it is clearly potentially a very useful scheme of improving the lives of people living with dementia.

Post post diagnostic care

In response to the issues raised about post post diagnostic care. Four possibilities are highlighted here:

1. Increasing the capacity of the dementia centre
2. Carer's listening service
3. Social prescribing as a mode of integration
4. Innovative Homecare

³¹ Self Directed Support - is it Right for You? http://www.moray.gov.uk/moray_standard/page_77505.html

³² <http://www.spaen.co.uk/>

³³ <https://www.iconnectne.org.uk/>

Increased capacity of dementia centre

The issue of getting appropriate information at the right times is important. There is no straight forward solution. As one participant put it: “This issue has been rumbling around for the 35 years that I have been working in the field and we’ve never quite worked it out.” The issue seems ultimately to be one of relationships and connections rather than just getting information. A good deal of information is shared informally through things like day centres, carer centres, cafés and of course via friends and neighbours. The key is to embed and connect good quality and up to date information into these various community settings. This has the benefit of not only providing adequate information, but sharing that information through the building of relationships. There are models available, such as PRESENT in East Dunbartonshire, which is quite an extensive model focussed around peer support and community connection³⁴. However, resources may be limited in terms of supporting a large organisation such as this and in practice, most people engage in such information exchange as part of their day to day work. The key within the city will be to coordinate the ongoing availability of up to date knowledge alongside of people who are able to communicate that effectively. So such things as Dementia Friends, Dementia Ambassadors along with other volunteers in other facilities such as the Living Well Cafés, or the kinds of initiatives highlighted in this report will be key in the process of enabling people to find post post diagnostic support and information. Likewise important initiatives by ACVO, such as their map of service provision across the city (which enables all citizens to find out what is happening in their area), their dementia friendly newsletter and the various resources they offer in relation to the third sector’s role in dementia care provide important points of information sharing and dissemination³⁵.

The Aberdeen Dementia Resource Centre, in conjunction with such initiatives, has the potential to provide the kind of information coordination necessary to fill this expressed gap in people’s experiences. However, there may be issues of capacity. With only one dementia adviser the Centre may be limited in its ability to deal with the issues being raised. This is not a criticism of the work of the centre which is clearly important and valued. It is a comment on capacity and the possibility that extended capacity might be required if it is to address this particular issue.

³⁴ Joint Improvement Team. ‘How PRESENT improves the wellbeing of people living with dementia in East Dunbartonshire: <http://www.coproductionsotland.org.uk/resources/resource-case-studies/how-present-improves-the-wellbeing-of-people-living-with-dementia-in-east-dunbartonshir>

³⁵ ACVO Dementia Friendly Communities <http://acvo.org.uk/resources/dementia-friendly-communities/>

Recommendation

There is no specific recommendation here. It is clearly an important ongoing issue which requires serious consideration. No obvious solution emerged from this project.

Carer's listening service

One of the things that emerged clearly from the conversations with carers was the fact that they often felt that they were not listened to. This resulted in frustration and sometimes anger. The sense of not being listened to sometimes applied to professionals apparently not hearing the key issues they wanted to focus on, but there was a deeper sense of not being listened to that lends itself to intervention. One way of responding to this sense of not being listened to would be to provide a space where people could be listened to, their grief acknowledged and potential options for health and well-being pointed out.

Via its participation in the *Community Chaplaincy Listening* project (CCL), Aberdeen City already has a model of care that, if creatively expanded and refocused specifically on people offering care to those living with dementia, could begin to address these particular needs. CCL is a mode of spiritual intervention (spirituality being understood in its broadest terms: meaning, purpose, hope, value, trust and for some people the divine) that is person-centred and well-being oriented. It assumes that the telling of a person's story enables them to find meaning, purpose and release even if there are certain things about their story that cannot be changed. Listening to stories is a significant person-centred and deeply therapeutic activity. CCL seeks to build resilience and enhance well-being by providing a listening service that enables a person to tell their story in the presence of trained listeners. Listeners explore questions of meaning and purpose as they work themselves out in the various stages of life's transitions. The task of the listener is not to answer questions but to take them seriously i.e. to allow a person to be fully heard, and to enable them truly to hear themselves. In this way people can discover their own way forward towards transformation and change thereby promoting positive self-management and promoting well-being.

Importantly, the process does not only involve listening, it also results in (or can do) social prescribing (see below). Once the listener has listened the chaplaincy listener then has the option to prescribe certain potential courses of action to the people they are listening to. So, the listener has in hand a range of health and social care options that can, in principle, help enhance the well-being of the person being listened to and the issues raised during the listening process.

This service is currently available ‘on prescription’ in a generic form via GPs and self-referral. However, it might be useful to consider a version that focuses specifically on the needs of people caring and supporting people living with dementia. This might mean training listeners to specialise in this particular area, or it may mean expanding the training of current listeners to include the more specialised issues that surround dementia. A more specialised version of CCL has real potential for addressing the issues around carers’ grief and feelings of not being heard highlighted previously. Benefits to health and well-being would include:

- *Giving a person the freedom to participate in intentional spaces where carers can speak out their grief and concerns in a safe, non-professional, non-stigmatising context. Sometimes feelings towards people with dementia can be difficult to experience and also difficult to articulate to family and friends for fear of judgment or recriminations. The freedom of the listening space offers what for some might be a unique opportunity just to be honest about how a carer feels.*
- *Increase a person’s resilience and sense of well-being by breaking down isolation and opening up new possibilities for action.*
- *Increasing carer’s awareness of the options that are open to them in dealing with certain issues and situations.*
- *Help to deal with the sense of grief that many carers feel by enabling its expression in a positive and safe environment.*

One issue that might be raised in relation to such a scheme is that many carers do not have a free hour to spend on such an endeavour. This returns us to the important issue of respite care which we have touched on previously. One way of addressing this concern might be to incorporate the idea of Community Chaplaincy Listening within the structure of Suzu-no-ya/church buildings. Within this context CCL could both complement the 24 hour hotline for carers and provide a context where volunteers or peers can provide cover to enable a person to spend time with a listener who would be available on site.

Recommendations

ACHSCP should consider entering into discussions with the Community Chaplaincy Listening service with a view to exploring the possibility of developing an aspect of the service specifically focused on those offering care and support to people living with dementia.

Social prescribing

In the previous section the idea of social prescribing was mentioned. It will be helpful to draw this out here. At this point it will be helpful to introduce an important idea: ‘social

prescribing.’ It seems clear from the focus group conversations that the GP is considered the hub in terms of information giving and treatment orientation by carers and people living with dementia. That being so, GPs are formative for the process of enabling people living with dementia to access the kinds of service that enable them and their families to live well. The idea of social prescribing suggests that alongside of the normal kind of medical prescribing that a GP engage in, he or she should have a variety of social options that can be prescribed. “Social prescribing is a way of linking patients in primary care with sources of support within the community. It provides GPs with a non-medical referral option that can operate alongside existing treatments to improve health and well-being³⁶.” Social prescribing might include referral to such activities as fishing clubs, gyms, sports, befriending service etc. Such prescribing is not only the domain of the GP but can apply to the referral work of any health and social care worker.

Arts on Prescription

We have seen how social prescribing might work within the context of a listening service. Another good example is the Arts on Prescription (AOP) program developed by HammondCare in Australia. AOP is an innovative new program which prescribes arts as an option for elderly people and people living with dementia. AOP is an engaging and practical program which brings together experienced artists to work with elderly people and people living with dementia to help participants to develop their creativity, to learn new skills and to reinforce the skill that they already have. The goal of the enterprise is to help recognise and meet the welfare needs of individuals at a holistic level. The prescribed programs run over an eight week period with participants attending one or two sessions per week. The classes were taught by twelve experienced artists specialising in a range of artistic forms such as painting, music, visual arts, theatre, photography and music. ‘Arts on Prescription’ Project Director, A/Prof Chris Poulos says “creating art can help with a range of wellness needs from anxiety, depression and fragility, to people experiencing social isolation or going through periods of bereavement. ... If someone is frail, lacking in energy or has a fear of falling, doing arts programs that increase their level of physical activity such as dance, singing, drama and movement will help improve their fitness, confidence, strength and balance. ... Art can also unlock a person’s creative side, giving them new interests to help them remain mentally active

³⁶ Centre for Reviews and Dissemination, the University of York. ‘Evidence to inform the commissioning of social prescribing.’ https://www.york.ac.uk/media/crd/Ev%20briefing_social_prescribing.pdf

as they age. ... Participants can be referred by their GPs, or they can refer themselves - but they will still need an 'Arts Prescription' form completed by their general practitioner. "A prescription helps reinforce the importance of proactive intervention and legitimises art being beneficial to regaining health just like traditional medicines that need a prescription." The program is open to people over the age of 65 who live at home and have unmet health and wellness needs. It is important to note that Arts on Prescription does not replace traditional healthcare or medical treatment. The program can however add a completely new dimension to the process of enabling and sustaining well-being.

The AOP program provides a good example of how healthcare that takes seriously the integrated nature of holistic care can bring together health, social care and in this case the humanities in order to ensure the well-being of elderly people and people living with dementia.

Heart for Art

A similar Scottish based initiative is the Heart for Art program³⁷. The 'Heart for Art' project, run by CrossReach, the Church of Scotland Social Care Council, is "a creative arts community operating across Scotland. It offers opportunities for people living with dementia and their carers to learn new or reawaken existing artistic skills, build confidence, and develop social relationships through creative arts, as well as providing access to support and advice. The project aims to challenge the stigma and discrimination associated with a diagnosis of dementia, by promoting positive images of people living with the condition. It also aims to improve personal relationships, promote mental and creative stimulation and create a community where members can participate in something that is meaningful to them." The program is funded by the Lifechanges Trust and currently runs in Glasgow, Edinburgh, Broughty Ferry, Stonehaven, Kirkcubright, Bankfoot and Garelochhead

Implications for Aberdeen City

The language of social prescribing helpfully illustrates and holds the tension between the language of health care and the language of social care. Finding a common language around key issues will be an important for task of ACHSCP in the longer term. ACHSCP should consider whether the language of social prescribing as a way of expressing the connection between medical health and social well-being approaches and interventions is worthy of further

³⁷ Heart for Art http://www.churchofscotland.org.uk/serve/the_guild/projects/current/heart_for_art

discussion and development. It should of course be recognised - as expressed by the GPs in this study - that the workload of GPs is increasing and that taking on responsibility for signposting social interventions might be difficult. This could be alleviated by an intentional and creative use of the third sector which is equipped to think through these issues and use the considerable assets that it has across the city. It should also be noted that the idea of social prescribing is not limited to GPs. As we have seen in the discussion around a carer's listening service, social prescribing can be carried out in different contexts by different groups of people. It is certainly the case that the people involved in this study felt that GPs were the communicational hub. However, there are other important ways in which social prescribing can be carried out.

Recommendations

1. ACHSCP engages in discussions with Gray's School of Art to explore the possibility of developing an equivalent to Arts on Prescription for the City. A simple starting point would be to get a group of students to put the idea together as part of one of their assignments. This could be a low cost or even no cost (at least initially) intervention that has significant impact on people's lives and mobilises a major institution within the city (Robert Gordon's University) to participate creatively in educating its students in relation to dementia and at the same time contributing significantly to the future of Aberdeen as a dementia friendly city.
2. ACHSP should consider the Heart for Art program as a possible way of meeting the desire expressed by people with dementia in this study to learn new skills and discover meaningful and creative things to do.
3. ACHSP should consider exploring the important potential within the third sector which could make the idea of social prescribing a practical success. This was something that the GPs in this study particularly emphasised.

Changing Attitudes

All of the people who participated in this study felt that the key to making Aberdeen a dementia friendly city lies in changing people's attitudes towards dementia. As one social work manager put it: "you don't so much need new initiatives; what you need is for people to look at things with new eyes: changing people's attitudes will change what we do for the better." A core task then is to change attitudes and explore new possibilities for creative care in the light of changed attitudes. How then might we go about changing people's attitudes? Here we will look at three possibilities:

1. Expanded befriending scheme.
2. Development of a Buddy system.
3. Changing the culture of care homes: Dutch Student initiative.
4. Empowering the carers of the future: Creating a dementia friendly generation.

Befriending

It is widely recognised that the best way to overcome stigma and develop positive images of others is simply by getting to know people. The problem of course for many people with dementia and those who offer them care and support, is that their social circles tend to shrink as the condition progresses. "He said "I don't really like to visit Bill. I prefer to remember him as he was." I was rather taken aback!" Friendship is a vital way in which stigma is overcome and positive attitudes are encouraged. But good friends can be hard to come by. The various dementia consciousness raising initiatives that go on within the city and across health and social care services (especially Dementia Friends, Dementia Ambassadors and Dementia Champions) were clearly held in high esteem. However, some people commented that the lack of any unified city wide strategy to facilitate friendship development was a significant issue. There are important befriending schemes within the city, for example, at Newhills Church and Sheddocksely Baptist Church. Previously there had been a city-wide scheme which had finished when its funding came to an end. People felt that this initiative had been very ably handled by ACVO³⁸. This has left a significant gap. Friendship is the essence of community and the foundation of the kind of positive identity that ACHSCP claims it wants for all of Aberdeen's citizens. Dementia friendly communities require dementia friendly people: people who can find time to be with and understand people living with dementia. Within Aberdeen city, this layer of relational development seems to be weaker than might have been expected.

³⁸ ACVO 'Befriending Partnership.' <http://acvo.org.uk/working-with/befriending-partnership/>

Thinking through issues around befriending could also have the added benefit of answering the deep concerns that some expressed within this study that there were people across the city who had few social support networks and who struggled to access some of the complexities of service provision (E.g. SDS). A well supported and effectively structured befriending scheme could function in a way that befrienders could also potentially have the role of supportive, collaborative advocates, particularly for people who struggle to find forms of support that can not only deal with their relational needs, but also help them deal with some of the more complex administrative aspects of accessing the system. During the first year following diagnosis, of course the dementia link workers, GP, CPN and so forth can have an advocacy role. But, as we have seen, there are issues around what happens after this. A well-managed befriending scheme could help alleviate some of the difficulties highlighted earlier in this report.

Recommendation

That ACHSCP revisits its city-wide friendship scheme and considers the possibility of revitalising it and putting it on a more stable and permanent basis. It would seem pertinent to re-open conversations with ACVO who have experience in developing and sustaining a scheme such as this. If it is the case that a scheme like this could be particularly valuable for people living with dementia who are vulnerable not only to loneliness but also to being excluded from accessing aspects of the system that could be beneficial for them, then this should be of immediate concern.

Re-thinking Homecare

Three issues seem to be paramount within the lives of people living with dementia:

1. The desire to have meaningful relationships.
2. The desire to have meaningful occupation.
3. The desire to remain at home for as long as possible.

Despite the desire for meaningful relationships, it is clear that one of the significant issues for many people living with dementia is their experiences of loneliest and isolation³⁹. In the previous section of the report it was noted that care homes can have negative images attached to them and that this might be an issue for care homes, care home workers and the perception

³⁹ Alzheimer's society *Dementia 2013: The hidden voice of loneliness*.

of care homes held by others along the dementia pathway. There it was suggested that care home facilities need to be viewed in the same life enhancing ways as other aspect of the dementia journey. One interesting initiative that seeks to address both of these issues is a scheme in Deventer in the Netherlands which allows students to live rent free alongside elderly residents, some of whom have dementia⁴⁰. The intention is to change young people's negative perceptions of ageing through encounter and experience. As the students encounter elderly people, so their opinions are changed and they bear witness in their lives to the value and goodness of older people. Likewise their involvement in the day to day life of the care home has been proven to be revitalising for staff and residents. The student becomes a resource for positive living and a potential catalyst for innovative change. In exchange for small rent-free apartments, the students pledge to spend 30 hours per month acting as "good neighbours." Students engage in a variety of activities with residents and offer company and encouragement as well as a sense of connection to "the outside world." In turn students gain the experience of friendships with people whom they may never have considered available for friendship. A similar scheme was introduced in Spain which has been replicated in more than 20 cities throughout that country. It is interesting to reflect on the impact that might be made on care homes if each home across the city had students living there and participating in the day to day activities of the institution.

This enterprise resonates with Shared Lives Plus that was mentioned previously in the section on respite care. Whilst the Netherlands initiative seems to have clear risks, which are not discussed in the somewhat sparse literature that looks at what is going on, the Shared Lives Plus approach has a similar goal, but with an established process that has been tried and tested in a variety of contexts⁴¹. The benefits for students (or others) and people living with dementia are immense. Students could find good, homely accommodation in a city where accommodation can be very expensive. The elderly person finds friendship and support and new possibilities for their future. Both in different ways become better and more dementia friendly citizens.

This approach offers one way to re-think aspects of care home provision (and home care more generally) in a way that moves it away from the assumption that its main focus is to manage the inevitable decline of the elderly person, towards a focus on wellbeing and life enhancement through positive intergenerational relationships. In principle this could enable

⁴⁰ *The Netherlands* (2015). 'Dutch nursing home offers rent-free housing to students.

⁴¹ Shared Lives Plus: <http://sharedlivesplus.org.uk/>

people better to develop independence, resilience and connectivity to their communities. This might cost more in the short term, but as models such as Buurtzorg in the Netherlands have shown, such initiatives can result in lower rates of dependence, higher rates of client satisfaction and lower costs in the longer term. Shared Lives Plus is not a substitute for ‘traditional’ models of homecare which require to be valued and adequately funded. It is a useful and potentially powerful innovation.

Recommendation

ACHSCP should consider exploring the possibility of utilising some derivation of Shared Living Plus’s approach to Homecare, with a view to reducing isolation and loneliness, increasing awareness of issues around dementia and offering the possibility for homes in general and care homes in particular to have the opportunity to be positively changed and challenged by the presence of non-professional and non-family carers.

Educating for a dementia friendly future: Mobilising schools

One of the most pressing things and the thing that people across the board felt was the vital foundation for all other positive change, was the need to help people to understand dementia and to develop ways in which everyone within the city can work together to bring about a positive change in people’s attitudes. One social care manager put it thus: “It’s not all about money. I think if people changed their attitudes everything else would be much easier. Changed attitudes lead to better understanding which makes for easier communication and better services.”

Educating children around issues of dementia and being alongside of people with dementia in both their primary and secondary education is a potentially important way of contributing to a dementia friendly future. There are at least three ways in which this has been done effectively.

The Memory Bridge Classroom experience.

Chicago based dementia care organisation *Memory Bridge*⁴² has a highly successful program for developing educational interchange between young people and people living with varying degrees of dementia. They have developed a 12 week curriculum-based after school program that teaches school pupils ages 10-17, how to be with and communicate with individuals with

⁴² Memory Bridge: The foundation of Alzheimer’s and cultural memory: <http://www.memorybridge.org/>

Alzheimer's disease and other forms of dementia. The aim is to develop intergenerational social and emotional skills in primary school pupils. Pupils are paired up with people living with dementia living in long-term care facilities within the vicinity of the school. The children are prepared by working alongside of social workers, and family members who gather stories and pictures about their “buddies.” The pupil meets with the person with dementia four times over the course of the 12 week curriculum. The program has significant benefits both for the children involved and for the people living with dementia whom they visit. For the children they are positively introduced to a group of people whom they would not normally come into contact with. As well as functioning to destigmatise dementia, this has benefits for the child’s emotional and social intelligence as well as their listening and relational skills. For the person living with dementia, they gain a sense of value and being meaningfully connected to the wider community. The curriculum is creative and innovative, using various approaches such as art, role playing and group discussion. Students learn about the brain, how memory works and how that learning applies to the ways in which they communicate with the people with dementia whom they visit.

Dementia awareness and intergenerational exchange in schools

The ‘Dementia awareness and intergenerational exchange in schools’ project has been run, tested and validated by the University of Worcester⁴³. The project was tested on 22 schools. Each school adopted a bespoke approach to designing a curriculum to enable effective teaching around issues relating to dementia. Like the Memory Bridge project, the curriculum included a practical component that meant students spent time visiting people living with dementia. In terms of impact, the program was shown to be highly successful in:

1. Increasing awareness of dementia;
2. Reducing stigma and fear;
3. Increasing the recognition of the importance and relevance of learning about dementia in schools;
4. Increasing awareness of how to help people with dementia to live well, and deal with the challenges and negative attitudes they may face.

In terms of impact, the program seemed to function on three levels:

⁴³ Bray, Jennifer and Atkinson, Teresa (2013) *Dementia Awareness Starts in School – A Group of Pioneer Schools in England Pilot Intergenerational Exchange*. In: NHS Healthcare Innovation Expo, 13th-14th March 2013, ExCel, London. (Unpublished)

1. *Impact on the pupils involved.* This included a greater awareness of dementia, greater understanding for the role of care and support and appreciation that people living with dementia can have a good quality of life.
2. *Impact on the teachers involved.* This included improved knowledge and greater understanding of dementia.
3. *Impact on the school community.* This included parents being able to have conversations about dementia with their children, a general improvement in dementia awareness, increased understanding by children of the caring responsibilities of parents.
4. *Impact outside of the school community.* Being involved with the project helped some carers to see their loved ones in a different way and reconnect with them. Taking part in the activities seemed to positively impact upon the people with dementia who participated. Increased community awareness due to involvement in the project.

Creating a dementia friendly generation

Creating a dementia friendly generation is a resource developed by the Alzheimer's Society. It comprises the resource was created to help schools tackle some of the misconceptions that surround dementia. It provides insights into dementia aimed at reducing stigma and providing opportunities for children to interact with people living with dementia. The resource is aimed at PSHE and Citizenship but overlaps with other areas of the curriculum for pupils ages 11-14 (design, technology, art, English). This program differs from the other two in that it is designed as a *whole school approach*. It has three core modules, but it also offers ways in which discussion of issues relating to dementia can be incorporated in other areas of the curriculum. So for example, creative writing in English or a focus on a poem on dementia; designing a memory game in Maths; exploring the biology of dementia in science; learning in PE how physical exercise can be protective from dementia; using key figures who have had dementia as a part of history lessons and so on. In this way this program aims to create dementia friendly pupils *and* dementia friendly schools.

Recommendation

ACHSCP should consider exploring models and approaches such as this that can enhance the educational experiences of school children and enable pupils to become dementia friendly people who are educated in dementia friendly schools. *Children are the carers of tomorrow.*

Key responses to the conversations.

Coordination and continuity of service delivery

- Schwartz Rounds
- The Esther Network

Care Provision: Finding respite

- The need for a new facility
- Creative use of care homes
- Shared Lives Scheme
- Shared respite
 - Community houses
 - coffee shop communities
- Creative use of Self Directed Support

Post post diagnostic support

- Information exchange strategy.
- Carer's listening service
- Social prescribing
 - Arts on prescription

Changing attitudes

- Befriending
 - Expanded befriending scheme
 - Buddy System.
- Changing the culture of care homes: Dutch student initiative
- Educating for a dementia friendly future: Mobilising schools.

Conclusions

The issues raised in this report have allowed us to gain some important insights into how some people are experiencing dementia services within Aberdeen City. These insights have in turn raised important issues which have produced some potentially useful innovations and possibilities. Whilst all of the innovations presented in the previous section have potential, in concluding this report it will be helpful to draw attention to what the author of the report considers to be strong practical possibilities that are actionable in the immediate future (not in order of priority). The relationship between the projects and the current Dementia Action Plan is laid out in the footnotes below. Each project maps on to one or more aspect of the plan. Page numbers relating to the concept's narrative and details of the recommendations are referred to in brackets.

1. Shared Lives Scheme/Shared Lives Plus Homecare⁴⁴ (p. 36 & 51).
2. Community houses/creative use of community buildings⁴⁵ (p. 37).
 - a. Carers listening service⁴⁶ (p. 44).
 - b. Arts on prescription⁴⁷ (p.46).
 - c. Heart for Art⁴⁸ (p.47).

[The suggestion here is that these three initiatives should be viewed as potentially working together within the same facility].

3. Development of a city wide befriending and advocacy scheme⁴⁹ (p. 49).
4. Development of Schwartz Rounds⁵⁰ (p. 27).
5. Care homes as places of respite and residence⁵¹ (p. 34).
6. Development of a network of coffee shop communities⁵² (p. 39).
7. Mobilising schools: Educating for a dementia friendly future⁵³ (p. 52).
8. Continuing to look at new ways to encourage the creative use of Self Directed Support⁵⁴ (p. 41).

⁴⁴ Outcome 4:4.3., Outcome 4.4.3.2., Outcome 5: 5.2., Outcome 6:6.1., Outcome 5:5.1.6.

⁴⁵ Outcome 3: 3.3., Outcome 4:4.3., Outcome 4.4.3.2., Outcome 5: 5.2., Outcome 6:6.1., Outcome 5:5.1.6.

⁴⁶ Outcome 1: 1.2., Outcome 5:5.1., Outcome 5:5.2., Outcome 6.6.1.2.

⁴⁷ Outcome 1: 1.1., Outcome 3.3.3.5.

⁴⁸ Outcome 1: 1.1., Outcome 3.3.3.5.

⁴⁹ Outcome 1.1.2.Outcome 3: 3.3.

⁵⁰ Outcome 5:5.3., Outcome 6:6.2., Outcome 6.6.5.4.

⁵¹ Outcome 4:4.3., Outcome 4.4.3.2., Outcome 5: 5.2., Outcome 6:6.1., Outcome 5:5.1.6.

⁵² Outcome 1.1.2., Outcome 1:1.2.3., Outcome 3.3.3.2.Outcome 3:3.3.

⁵³ Outcome 1: 1.1

⁵⁴ Outcome 4:4.3., Outcome 4: 4.3.4.

All of these projects have the potential to have a positive impact upon dementia services within the city and to improve the lives of people living with dementia and their families in significant ways. Importantly, each has the potential to change the culture of the city in a way that can facilitate the creation of a dementia friendly city that contains dementia friendly citizens who understand the meaning of dementia friendly communities. They have the potential to bring together various aspects of the city's culture around the experiences of people living with dementia (education, business, religious communities, families, diverse health and social care professionals etc.) The key is that each initiative, in different ways, is intended to grow and facilitate the kinds of communities (voluntary and professional) that are needed if Aberdeen City is to be dementia friendly in the long and the short term. In creating lay and professional communities that care, we can discover new possibilities for people with dementia and their carers and supporters to live well even in the midst of the inevitable challenges that dementia brings with it. It is appropriate to leave the penultimate words of this report to Christine Bryden, someone who lives with dementia:

“How you relate to us has a big impact ... You restore our personhood, and give us a sense of being needed and valued. Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. We're still here, in emotion and spirit, if only you could find us.”

The task of genuinely person centred health and social care is to ensure that people are never lost and always found.