

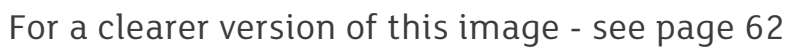
Independent Advocacy for People Living with Dementia and Unpaid Carers

A Scoping Study

Charlotte Lee, March 2016

CSL Training, Evaluation and
Development





Acknowledgements

We would like to thank everyone that has been involved in this study for taking the time to meet with us or to complete a survey. We recognise the different pressures that people have on their time and energy.

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We would also like to thank the Scottish Independent Advocacy Alliance (SIAA) and others for circulating information about this study, and the relevant surveys, to people and organisations it would otherwise have been difficult for us to make contact with.

Finally, we would like to thank The Advocacy Project in Glasgow and the Alzheimer Scotland Head Office in Edinburgh for hosting stakeholder meetings with advocacy organisations and others. We are very grateful for their support and hospitality.

Charlotte Lee, Karen Irvine, Amanda Scott and Christina Wallace

Foreword

Much is said about human rights internationally and here in Scotland, yet there is no explicit human right to ‘a voice’. This is somewhat concerning because in order for a person to secure their human rights they usually need to be heard or, at least, we need to know what they would want. It must, however, be the case that the right to a voice is implicit to all human rights legislation, conventions, principles and charters otherwise those who have no voice – for whatever reason – will struggle to secure their rights and may find themselves ignored, treated unfairly or even abused.

This report shows that in Scotland today we could be doing much more to give people living with dementia, and carers, a voice. It’s not a new discovery; we have known it for many years, particularly through the excellent work of Jan Killeen (formerly of Alzheimer Scotland) carried out 20 years ago. Scottish legislation contains various rights to independent advocacy, and duties are placed on public bodies to provide or consider providing advocacy, so the framework for success appears to be there. However, the right to advocacy is not being made real for many and this is a key factor in preventing people from claiming their human and statutory rights.

The Life Changes Trust commissioned this work by Charlotte Lee and colleagues in order to establish ‘where we are at’ with independent advocacy and dementia in Scotland in 2016. This report sits within a wider programme of work funded by the Trust between 2013 and 2023. Four key themes within all the work of the Trust are: empowerment of the individual (including financial empowerment), early intervention, the power of relationships and human rights made real. These themes are demonstrated in practical ways through the projects the Trust funds.

Empowerment of the individual

Individuals who do not have a voice are disempowered. The degree to which they are disempowered and the consequences of such disempowerment will vary. By contrast, individuals who are given a voice – either their own or the voice of another on their behalf – will be far more likely to achieve their aims and wishes. For example, there are many people living with dementia today who are unable to claim self-directed support because they have no voice to challenge or influence the process.

Early intervention

As this report testifies, intervention often takes place at a time of crisis and distress and requires fast decision making. Although there are occasions where a crisis first highlights a problem or risk, some events are predictable. For example, knowledge that there will need to be a transition from the home to a care home; or hospital to home; or the appointment of power of attorney. The involvement of an independent advocate at an early stage can be invaluable and prevent much stress and complication further down the line. This is particularly true if there is disagreement amongst relatives as to what the correct course of action should be.

The power of relationships

Sometimes a person diagnosed with dementia can feel like they have lost their sense of individuality. They have now become one entity with their family carer, and are viewed by service providers as such – and carers can experience the same. A relationship of trust that affirms individuality can be built with an independent advocate because they will focus solely on the needs and aims of the individual. When a person has a good relationship with their independent advocate, and that advocate is shown respect by service providers and others, solutions can be found more swiftly and the pressure felt by a carer can be relieved. It can also have a positive impact on the relationship between the person with dementia and the carer.

Human rights made real

It can be almost impossible for some people to secure their human rights if they have no access to an independent advocate (whether instructed or non-instructed). Particular rights that might be affected could be:

- The right to liberty and security (Article 5, European Convention on Human Rights)
- The right to respect for family or private life (Article 8, ECHR)
- The right not to be subjected to inhuman or degrading treatment (Article 3, ECHR)

We can all think of examples that fit these categories; we can also see that without a voice these rights can easily be taken away from people.

If we are serious about taking a human rights based approach to dementia in Scotland, we need to start grappling with these issues. We need to examine what is happening on a day-to-day basis and consider whether we really are hearing the voices of people living with dementia and their carers – in all care settings. Independent advocates are in a prime position to highlight what is working well in Scotland and what is not, for example, in relation to self-directed support or post-diagnostic support. They are also well placed to play a key role in helping secure rights and represent individuals where rights need to be balanced against each other, which is often the case.

The Life Changes Trust will now consider the key findings of this report in light of the work it is carrying out to create better lives for people living with dementia and their unpaid carers. As a strategic funder, we will take an approach that has the potential to be transformational and sustainable.

We would like to thank Charlotte, Karen, Amanda and Christine for their superb work. We are also very grateful to all those people who gave up time to meet and discuss independent advocacy and dementia or complete a survey.

We trust that you will find this report informative, challenging and inspiring.

Anna Buchanan

Director, People Affected by Dementia Programme

October 2016

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Setting the Scene

Background

This exploratory study was commissioned by the Life Changes Trust with the aim of developing a better understanding of how independent advocacy can be of benefit to people affected by dementia (both those living with dementia and carers).

As well as increasing knowledge about this vital area of provision, the Trust will use the findings to decide whether there should be further investment or influencing activities to promote the use of independent advocacy for people affected by dementia.

The main aims of the study were to find out more about:

- The role that independent advocacy does or could play for people living with dementia and carers at various stages throughout the dementia journey.
- What independent advocacy is available and where there are gaps in independent advocacy provision for people affected by dementia in Scotland.
- The most appropriate model(s) of independent advocacy for people with dementia and their carers.
- How access to independent advocacy for people with dementia and their carers could be improved.

Dementia in Scotland

The information in this section is drawn from Alzheimer Scotland's website www.alzscot.org.

Dementia is the progressive loss of the powers of the brain. There are many kinds of dementia but the most common is Alzheimer's disease. Other kinds of dementia include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick's disease) and alcohol-related dementias. It is also possible to have more than one type of dementia: for example, Alzheimer's disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should.

In Scotland, over 90,000 people have dementia. It is most common in older people but can affect people in their forties or fifties, or even younger.

What causes dementia?

We do not yet know exactly what causes dementia. Medical researchers all over the world are working to find causes and develop treatments.

Alzheimer's disease damages individual brain cells one by one, so that the brain can't work as well as it used to. A protein called amyloid builds up in deposits, called plaques, and tiny filaments in the brain cell form tangles. Much current research is trying to find out why these changes happen and what can be done to stop them.

Some rare kinds of Alzheimer's disease affecting people under 65 can be inherited. Faulty genes may cause the build-up of the amyloid protein. Recent research seems to show that there may also be a genetic factor in other cases of Alzheimer's disease. However, this does not mean that someone whose parent had Alzheimer's will automatically develop the disease.

In the **vascular dementias**, there are problems with the blood supply to brain cells. For example, some people have tiny strokes (or infarcts) which damage small areas of the brain.

In **frontotemporal dementias** the parts of the brain responsible for decision-making, control of behaviour and emotion and language are affected. It is not fully known how this happens but there seems to be an abnormal growth of some types of proteins in the brain cells. In around 30-50% of cases of frontotemporal dementia, the person may have a family history.

Dementia with Lewy bodies is caused by small, round clumps of protein that build up inside nerve cells in the brain. The protein clumps damage the way brain cells work and communicate with each other. The nerve cells affected by Lewy bodies control thinking and movement.

What are the symptoms of dementia?

Every person with dementia is different. How their condition affects them depends on which areas of their brain are most damaged.

One of the most common symptoms of dementia is memory loss. Everyone forgets things sometimes and most people's memory gets worse as they get older. But when someone has dementia, they may forget the names of family members, not just of strangers. They may burn pans because they have forgotten them or forget whether they have eaten lunch. They may repeat the same question again and again and not know they are doing it.

People with dementia may lose their sense of time, losing awareness of which day it is or of the time of day. They may lose track of where they are, and get lost even in a familiar place. They may fail to recognise people they know well.

People with dementia may often be confused. Their ability to think, to reason and to calculate can all be affected. They may make odd decisions and find it hard to solve problems. Handling money may become difficult as they find it harder to work out their change or lose their sense of the value of money.

Dementia can also cause personality and behaviour changes. Someone who was active and energetic may become listless, someone pleasant and well-mannered may become rude and aggressive. These changes can be particularly distressing to relatives and friends as they lose the person they knew.

Gradually, over a period of years, most functions of the brain will be affected. Eventually, people with dementia will probably need help with even simple daily activities, such as dressing, eating or going to the toilet.

Although there are no cures, much can be done to ease the impact of the condition, and to maintain the best possible quality of life for those affected. It is important for people with dementia that their interests, skills, and normal life are supported and maintained for as long as possible. Also that their rights are recognised and their capacity to make choices is supported, even if this is limited.

What is Independent Advocacy?

The information in this section has been taken from ‘The Principles and Standards for Independent Advocacy’ produced by the Scottish Independent Advocacy Alliance (SIAA) in 2008.¹

Independent advocacy aims to help people by supporting them to express their own needs and make their own informed decisions. Independent advocates support people to gain access to information and explore and understand their options. They speak on behalf of people who are unable to speak for themselves, or choose not to do so. They safeguard people who are vulnerable or discriminated against or whom services find difficult to support.

Advocacy is about broadening horizons and widening the options that people have. It is about speaking up if you notice that something is wrong. An effective advocate will observe the whole person and all aspects of their life. They will notice what is wrong in the person’s life, things that the person tolerates perhaps because they do not know anything different, and tries to address them.

1 <http://www.siaa.org.uk/publications/principles-standards/>

Different Types of Advocacy

Citizen Advocacy

Citizen advocacy is when ordinary citizens are encouraged to become involved with a person who might need support in their community.

The citizen advocate is not paid and not motivated by personal gain. The relationship between the citizen advocate and their advocacy partner is on a one-to-one, long term basis. It is based on trust between the partner and the advocate and is supported but not influenced by the advocacy organisation. The advocate supports their partner using their natural skills and talents, supplemented with relevant support, information and training specific to each advocacy partnership, in augmentative communication, for example.

Group or Collective Advocacy

Collective advocacy is where a group of people who are all facing a common problem gets together on a formal basis to support each other over specific issues. Individual members of the group may also support each other over specific issues. The group as a whole may campaign on an issue that affects them all. A collective voice can be stronger than that of an individual, as groups are more difficult to ignore. Being part of a collective advocacy group can help to reduce an individual's sense of isolation when raising a difficult issue.

Peer advocacy

Peer advocacy is when individuals share significant life experiences. The peer advocate and their advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and empathise with their advocacy partner. Peer advocacy works to increase self-awareness, confidence and assertiveness so that the individual can speak out for themselves, lessening the imbalance of power between the advocate and their advocacy partner.

Professional advocacy

Professional advocacy is also known as one to one, individual or issue-based advocacy. It is provided by both paid and unpaid advocates. An advocate supports an individual to represent their own interests or represents the views of an individual if the person is unable to do this themselves. They provide support on specific issues and provide information but not advice. This support can be short or long term.

Non-instructed Advocacy

Non-instructed advocacy happens when a person who needs an independent advocate cannot tell the advocate what they want. This may be because the person has complex communication needs or has a long-term illness or disability that prevents them from forming or clearly stating their wishes and desires. This usually takes place with people who have dementia or profound and/or severe learning difficulties.

“At the heart of advocacy is a commitment to safeguarding the rights of the most vulnerable, and non-instructed advocacy is a practical manifestation of that commitment. The challenge is to develop the skills and confidence of advocates to work in this way, and to raise awareness amongst others of the legitimacy of this approach.”

(SIAA leaflet – Non-instructed Advocacy Guidelines 2009)²

“When independent advocacy was first described as a way of supporting people to have a voice, it relied very much on instruction. That is, the person needing the support of an advocate would tell the advocate what to do on their behalf. This meant that the individual requested the support of an advocate and were able to tell them what was wrong.

A generally held view was that, if an individual couldn’t understand what an advocate was, and was unable to instruct them with regard to what they wanted, independent advocacy was not a suitable service for them. However, there are no other services based so strongly around the principles of independence, confidentiality and empowerment, and which put people first at all times.

2 <http://www.siaa.org.uk/publications/non-instructed-advocacy-guidelines/>

This left a big problem regarding the very many people unable to instruct, but who were facing many disadvantages and difficulties in their lives, and in some cases experiencing poor or abusive treatment. These were often people who really needed the support of an independent advocate most of all, for example, people with learning disability, older people with dementia, or people with mental health problems.

Advocates who thought independent advocacy should be available to everyone started to consider how non-instructed advocacy might work.”

(Rick Henderson, Action for Advocacy, ‘Non Instructed Advocacy in Focus’ 2007)³

“The core of Non-instructed advocacy is the use of the Watching Brief, a process by which an advocate generates questions on behalf of their advocacy partner. In essence, the advocate asks questions that any reasonable person would have asked in the same circumstances.

For any proposal, planned or actual, the advocate looks at how it impacts on the life of the advocacy partner.”

(‘An Advocate’s Guide to Independent Non-Instructed Advocacy, Older People and Dementia: Principles, Practice and Guide to Further Resources’, 2013, Rebecca Colclough, Age Concern Cardiff and the Vale of Glamorgan)⁴

3 http://www.aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf

4 <http://opaal.org.uk/app/uploads/2015/09/An-Advocates-Guide-to-Non-Instructed-Advocacy-2013.pdf>

Methodology

This was a relatively brief study that aimed to provide a snapshot of the current situation with regard to the availability and accessibility of independent advocacy for people affected by dementia and demonstrate the impact independent advocacy has had or could have. In undertaking this study we:

- Carried out a brief literature review of relevant publications, policy and legislation to develop a greater understanding about the current position with regard to examples of good practice and key 'drivers' for change. Information from the literature review has been included within this report.
- Held two stakeholder meetings, one for advocacy organisations and one for other interested parties from statutory and voluntary organisations. These sessions were supplemented by a number of interviews with other stakeholders.
- Developed and analysed responses to surveys from 17 advocacy organisations, 10 advocacy commissioners, 4 people affected by dementia and also 20 other relevant stakeholders.
- Identified and visited three focus areas (the Western Isles, North Lanarkshire and Angus) representing different advocacy approaches as well as a mixture of urban, rural and island communities. During these visits we carried out individual and group interviews with:
 - 38 people affected by dementia;
 - 9 advocacy managers, staff and volunteers;
 - 3 advocacy commissioners; and
 - 40 representatives from other statutory and voluntary groups.

The advocacy organisations we visited were:

Advocacy Western Isles

www.advocacywi.co.uk

Advocacy Western Isles (AWI) provides a free, independent and confidential service throughout the Western Isles.

It works on the basis that advocacy is about being supported to speak up for yourself, defending your rights, promoting your interests and ensuring that your voice is heard.

The service is available to adults, individuals with learning difficulties, those experiencing mental health issues, and children and young people.

AWI can link people to a trained Advocacy Worker who can support them in practical ways.

AWI recognises that the number of people with dementia who currently access their service is relatively small. This is an area AWI would like to develop and have begun to make connections with relevant statutory and voluntary organisations that have a role to play in supporting people to live well with their dementia. AWI are also actively seeking funds to progress this area of work.

Angus Independent Advocacy

www.angusindadvocacy.org

Angus Independent Advocacy (AIA) is an independent organisation working alongside vulnerable people to help them have their voice heard and safeguard their rights. They work with people who are at risk of being unable to safeguard their rights through Mental Ill Health, Learning Disability, Dementia, Frailty in Old Age or Acquired Brain Injury.

AIA currently respond to referrals from people requiring advocacy support. Often people with dementia are referred once they have been admitted and detained in hospital through the Mental Health Care and Treatment (Scotland) Act (2003). AIA are currently trying to readdress this imbalance through the citizen advocacy project – seeking people out and offering long term preventive advocacy as early as possible after their dementia diagnoses. One worker is targeting her resources at Kirriemuir.

They have also applied for further funding to work with older people through Health and Social Care Integration. One of the aims is for the worker to be really connected to referral pathways for people with dementia so they can support people as early as possible and access timely and appropriate support.

Recently a younger person came to AIA office looking for support. He has a diagnosis of vascular dementia and has had to give up his work. Due to this and other reasons he is about to lose his home for missed mortgage payments. They want to get to people before these major crises arise to provide preventative independent advocacy.

In the previous twelve months AIA provided independent advocacy for 25 people with dementia.

Equals Advocacy Partnership

www.equalsadvocacy.org.uk

Equals Advocacy Partnership provides an independent advocacy service for older people aged 65 + in North Lanarkshire. The service is provided by a small team of staff and volunteers.

They provide a core service which mainly responds to legislative work, but more recently they have been given the opportunity to deliver a more preventative advocacy approach. The preventative advocacy service helps people who have recently been diagnosed with dementia and their carers to plan for the future. They encourage people with dementia to consider Power of Attorney, anticipatory care plans, advance statements and also provide them with information on services available to help keep them well and in their own homes living as independently as possible. All staff and volunteers are trained in dementia and also have an awareness of the issues that affect someone caring for their relative with dementia.

Equals Advocacy Partnership have supported a total of 555 older people during the period April 2014 to March 2015 in the core service and 246 people through the additional preventative advocacy service. Approximately 60% of referrals are people with dementia and their carers. The forecast for the period April 2015 to March 2016 shows an increase which is not surprising given the increasing elderly population.

In September 2013 the Reshaping Care for Older People Steering Group approved the release of funding to Equals Advocacy Partnership to deliver a **preventative advocacy** service to older adults aged 65 and above who reside in the North Lanarkshire area. The service focused on reaching people at an earlier stage before they were subject to any legislative intervention and targeted individuals who were unconnected to services.

The funding allowed the service to Provide Future Planning surgeries in the 6 localities (promoting Power of Attorney, anticipatory care plans, advance statements, etc.).

The overall aims met by the service were:

- Providing older people/carers with relevant, accurate information that can help them stay independent and in control of their lives
- Helping them to navigate through the system to address their needs
- Ensuring they have access to services and support in their communities to keep them active, fit and well

This was achieved by expanding the range of existing paid advocacy workers and by developing a pool of volunteer advocacy workers.

The service became operational in December 14 and Equals Advocacy Partnership clearly evidenced the need for a more preventative and anticipatory advocacy service. Equals has supported a total of **369** older people with one to one advocacy in North Lanarkshire during the period December 13 until January 15.

This project has demonstrated the impact that a preventative advocacy approach can have. In particular, if we provide advocacy at the point of diagnosis then we can help older people and their carers plan ahead to ensure they have a better quality of life.

Ceartas

www.ceartas.org.uk

We met with staff from Ceartas Advocacy in East Dunbartonshire as they have a well-established approach to providing advocacy for people affected by dementia. We believe that their experience has a valuable role to play in considering how best to take things forwards.

Ceartas (cyɹ-tas – pronounced KEIR-tis) is a Gaelic word meaning ‘equality, justice and fairness’. These are the values promoted through their work with the people of East Dunbartonshire. Ceartas is an independent charity, guided by oversight and top-down direction from its Board of Directors, and also guided by involvement and bottom-up direction from its service users.

Ceartas is a membership organisation. Anyone who has an interest in the work and supports the values that Ceartas promotes can apply to be a member and demonstrate their support of Ceartas' work. Members are kept informed of Ceartas' work and able to shape their future work and priorities as they involve service users and members in their planning. Members can attend the Annual General Meetings, and are eligible to vote to elect the Board of Directors.

Mission Statement:

“Ceartas provides an advocacy service for people in East Dunbartonshire irrespective of their cultural background, gender, beliefs or sexuality.

We are committed to providing a service based on the principles of equality, fairness and justice. We strive to ensure that the views and opinions of individuals are heard and respected, affecting in a positive way the lives of people using the service.

We have a responsibility to provide this service, ensuring the rights of individuals are always central, in compliance with national advocacy standards.”

There are a number of approaches undertaken by Ceartas which we feel other advocacy organisations could learn from around providing advocacy for people affected by dementia:

- **G.P. Work** (in 2 practices) When patients and relatives come to the surgery for a dementia review, they have a lengthy appointment and will have dedicated time with the advocacy worker in the same afternoon. This results in patients feeling well supported and, although the support of advocacy is often not required until much later, service users have said that it is important to know that the support is there, as well as the support around practical issues such as Power of Attorney.
- **De Café** started in 2005 as a way to introduce people to advocacy work, and provide a forum for people with dementia, and their carers, to come together for support and information about living with the condition, and find out about other services in the area. It meets monthly in 3 venues across East Dunbartonshire – Kirkintilloch, Bishopbriggs and Milngavie.

- **Ceartas Dementia Voices** is for people living with dementia and their carers, who want to influence dementia services across East Dunbartonshire. This group complements De Café. It is a task-orientated group ensuring that people living with dementia are consulted about local and national developments, and can make their voices heard. It meets quarterly, and is intended for people with a diagnosis of dementia, as well as their friends, families and carers.
- **Still Game** is designed for current and former service users who ‘want to give something back’, and meets in the Ceartas office on the first Tuesday of the month from 12.30 – 2.30. It aims to give regular opportunities for people to have their say about Ceartas, to encourage them to contribute to decisions, and the future development of Ceartas, to get more involved in the organisation, and to get together and have fun! They have held interviews for new staff, indicating the qualities they would like to see, suggested changes to improve the Advocacy Guide booklet, and provide regular reports to the Board of Ceartas.

For the previous 12-month period Ceartas had provided advocacy for 112 people with dementia and 16 carers.

Independent advocacy available to people affected by dementia

Anyone with dementia, regardless of the stage of their condition, has a right to access independent advocacy under the **Mental Health (Care and Treatment) (Scotland) Act 2003**.⁵

“Every person with a mental disorder shall have a right of access to independent advocacy; and accordingly it is the duty of —

- (a) each local authority, in collaboration with the (or each) relevant Health Board; and
- (b) each Health Board, in collaboration with the (or each) relevant local authority, to secure the availability, to persons in its area who have a mental disorder, of independent advocacy services and to take appropriate steps to ensure that those persons have the opportunity of making use of those services.”

The Code of Practice⁶ which underpins how the Act should be implemented defines what it means by ‘independence’:

“Independent advocacy should be provided by an organisation whose sole role is independent advocacy or whose other tasks either complement, or do not conflict with, the provision of independent advocacy.”

There are sixty-three advocacy organisations contained in the directory of advocacy organisations on the SIAA website. This directory includes a ‘Find an Advocate’ function which shows what independent advocacy is available in each of the thirty-two local authorities across Scotland. It includes a brief description of the type of advocacy provided and who is eligible to access it.

What we found when doing a search of this directory, based on the eligibility criteria stated, is that independent advocacy is available for:

- People with dementia in ten local authority areas.
- People with mental health problems in thirty local authority areas
- Anyone using community care services in one area

⁵ <http://www.legislation.gov.uk/asp/2003/13/contents>

⁶ <http://www.gov.scot/Publications/2005/08/29100428/04289>

- Anyone in one local authority area
- Older people in twenty-four local authority areas
- Carers in ten local authority areas
- People with alcohol related brain damage in two local authority areas

The directory provides a link (where available) to the advocacy organisation's website. Making use of this function we were able to identify a further three local authority areas where dementia was included in the eligibility criteria and one area where older people were included.

The above information does show that, in line with their statutory duties under the Mental Health Act, local authorities and their NHS Board partners have ensured that there 'technically' is independent advocacy available to people with dementia as they will be covered under the mental health criteria. Similarly, carers of people with dementia may also be able to access advocacy under criteria such as mental health or older people.

However, there are a number of **potential difficulties**, even before considering whether the amount of independent advocacy available is sufficient to meet the potential demand. In particular:

- people with dementia may not identify themselves as having mental health problems and therefore may not think that independent advocacy is available to them in twenty of the thirty-two local authority areas (or seventeen if they also accessed advocacy organisations' own websites);
- the possibility that the added stigma associated with alcohol related brain damage could mean that there may be reluctance to access such a specialist resource;
- where carers are not specifically included in the eligibility criteria they may be unlikely to recognise that they could potentially gain access under the criteria of older people (where this applies to them) or mental health, etc;
- the stated criteria of using community care services in one local authority area may mean that people who are either pre-diagnosis or not at a stage where they need to access formal services are excluded.

Why independent advocacy is important for people affected by dementia

“Many people in society are disempowered by systems which have a significant effect on almost every aspect of their lives. These are people who are disempowered to such an extent that they are unlikely to be able to fulfil their basic human needs or demand their basic human rights. A person’s initial hopes and dreams can be severely limited by this.

Independent advocacy can help to widen a person’s horizons and enable them to become active members of society”.

[‘Principles and standards in Independent Advocacy organisations and groups’, Advocacy 2000 (2002)]

Any of us could find ourselves in a situation where we are unable to speak up for ourselves or the people we care about. For example, we could become unwell or have an accident, we could lose our confidence through becoming unemployed or experiencing a bereavement.

“However, some people in society are much more likely than others to be treated unfairly because of other people’s prejudice and/or because of individual, social and environmental circumstances that make them vulnerable. Factors which might put people at risk include age, physical frailty, disability, gender, ethnic origin, sexual orientation, impairment (cognitive, psychological, motor, sensory), reputation, dislocation, abuse, family breakdown and social isolation.”

(‘Independent Advocacy – A Guide for Commissioners’, Scottish Government 2013)⁷

The reasons that people with dementia need advocacy are unlikely to have changed significantly since ‘Advocacy and Dementia’ by Jan Killeen (Alzheimer Scotland) was published in 1996⁸:

⁷ <http://www.gov.scot/Publications/2013/12/7000>

⁸ <https://www.amazon.co.uk/Advocacy-Dementia-Jan-Killeen-x/dp/0948897244>

“People with dementia need advocates for four key reasons:

- They may be vulnerable to physical, emotional and financial abuse
- They need support at times of transition when a major decision about their future has to be reached
- To ensure they receive their legal entitlements
- To safeguard the quality of their care”

Scottish Government guidance published recently⁹ about carers’ advocacy states that:

“Carers should be involved in decisions about their own care and support. They can also be involved in decisions about the care and support of the person they care for. Advocacy helps ensure that people’s rights are upheld by ensuring that their views, opinions and wishes are expressed and listened to when decisions are made about their lives. Advocacy should provide an environment where people can confidently raise issues, knowing that it is free from conflict of interests.”

‘Remember, I’m still me’¹⁰ the report from the Care Commission and Mental Welfare Commission Scotland’s joint visits to care homes in 2009 acknowledges that older people living in care homes are some of the most vulnerable people in society. They depend on the staff that look after them to ensure that they receive the best possible care. However, sometimes staff delivering care can ‘forget’ the person inside the dementia, making the need for independent advocacy all the more evident.

They also found that although reviews of care were being carried out regularly (approximately once a year for most people residing in the 30 care homes visited for the report) the quality of the reviews carried out varied. These reviews were found to rarely involve the person themselves, usually taking place with staff members and a friend or relative, with little evidence of involvement from a social worker, GP or other professional. Another point raised in this report was that only 24% of people had an adequate record of their life history with the majority not having enough information noted regarding their personal preferences recorded in their personal plan. It was also noted in this report that staff were found to have little or no understanding of the legal safeguards in place for people with dementia and who had legal powers regarding a person’s welfare.

9 <http://www.gov.scot/Publications/2016/03/5362>

10 http://www.mwcscot.org.uk/media/53179/CC__MWC_joint_report%20Remember%20Still%20Me.pdf

Other potential advocacy issues included in the report were:

- Around half of the residents never go out
- Very limited activities available – not tailored to the individual
- The environment not being dementia friendly
- Inappropriate prescribing – 75% of residents on 1 or more psychoactive drugs, despite known risks
- Nothing in care plans about other ways to deal with aggressive or challenging behaviour- medication should be the last resort
- The use of locked doors – with no personal plans about why someone needs to be locked in, very few people having freedom to come and go

Similarly, potential advocacy issues are also raised in the Mental Welfare Commission's report from visits to continuing care wards in 2014 Dignity and Respect – Dementia Continuing Care Visits:

- Only half of the units had advocacy input in the last 6 months
- Only half of the people who were stressed/distressed had a care plan in place - a quarter of patients had generic care plans
- 43% were not receiving adequate stimulation – social/recreational
- 73% hadn't been outside in last 3 months - 53% hadn't been out in previous month – even though the visit was in summer
- Only half had a dementia friendly environment – some were still small dormitories with shared facilities

The Charter of Rights for People with Dementia and their Carers in Scotland (published October 2009, by the Cross-Party Group in the Scottish Parliament on Alzheimer's)¹¹ indicates that the Charter is required as it is widely recognized that those with dementia and their carers face cultural, social and economic barriers to fulfilling their human rights as well as the impact of the condition itself.

- **The nature of the condition:** Over time the condition affects the capacity of individuals to make some or all decisions about their everyday life, including their money, health and wellbeing. It gradually affects the ability to communicate, reason and act in their own interests and protect their own rights. This can lead to individuals with dementia being at greater risk of violence, injury or mental abuse, neglect or negligent treatment, maltreatment and financial exploitation.

- **Inadequate or inappropriate services:** There is evidence from research that those with dementia and their carers often do not receive the proper support, care and treatment they need to continue to live fulfilling lives.
- **Attitudes in society:** People with dementia still face stigma and discrimination in society as well as a lack of equality of access to high quality dementia services. Awareness raising campaigns are beginning to change public attitudes, however, changing attitudes and practices to ensure the rights of people with dementia are fully recognised continues to be a major challenge for bodies responsible for providing health and social care.
- **Unmet needs of carers:** Caring for someone with dementia can be stressful due to the complex, unpredictable and progressive nature of the condition and may have profound social, emotional, physical and financial impact on carers, including increased risk of stress-related conditions such as depression. Many carers feel their views and needs are overlooked by health and social care professionals and that their right to support as partners in the provision of care is not well recognised.

These rights form a fundamental and easily accessible basis for use when advocating for the person's rights, needs or wishes.

Many people with dementia and their carers will have had no contact with the social care or welfare benefits system prior to the dementia reaching a stage where it is having a significant impact on their day to day lives. Understanding and coming to terms with the dementia itself is a daunting enough task without having to navigate the complexities of 'the system'. This is reflected in the following quotes from people involved in this study:

"You don't know where to go or who to ask for help. It's like being on a desert island." (interview with a carer)

"There are many situations where people with dementia or carers will not

automatically receive a package of care and support that meets their needs without significant work with providers and navigation of complex systems in health and social care. People who are ill, not experts in how these systems work or under emotional stress, need to be able to access support to make their case and ensure that the best possible care and support is made available to them.” (Alzheimer Scotland)

“Advocacy has a key role to play for carers who are ‘floored’ by the diagnosis and watching their relative deteriorate as the illness develops.” (Interview with someone from a Voluntary Organisation)

From our discussions with people and the responses received to surveys there are a number of issues faced by people affected by dementia that may increase their need for independent advocacy. Common themes included:

- Being isolated – either through living in remote and rural areas or having no-one in their lives
- Not being listened to by people making decisions which affect them
- Being treated on general rather than dementia wards and being kept in hospital too long or sent home too early
- Services not being flexible or person centred in spite of the anticipated move towards self-directed support
- A focus on protecting people rather than supporting their independence or decision making
- Limited range of services and support on offer – a particularly common theme being that once people need more than a very small amount of home care (often limited to ‘life and limb’) the only option available to them is a hospital or care home

“Research shows that even when an older person may be surrounded by family or professionals on whom they are dependent for care and support, they may still feel powerless or unable to voice their opinions. In such circumstances, they may find it daunting or feel unable to influence or challenge major decisions that are made about and impact on their life, further reinforcing their sense of powerlessness.”

“The availability of independent advocacy should be regarded as an important hallmark of good quality residential provision for older people. It is a key factor in providing a service which puts the resident at the forefront of provision rather than systems, processes and routines. It is a crucial means by which older people in residential homes can be empowered to say what they want, secure their rights, represent their interests and receive the specific services they need.” (‘Voice, Choice and Control’, Older People’s Commissioner for Wales, 2012)¹²

Independent advocacy organisations were asked to identify the top four reasons why people with dementia or their carers have accessed independent advocacy over the last twelve months. These were:

- Decisions being made about the need to move from home to a care home or hospital
- Use of legal powers being considered, e.g. Guardianship, Power of Attorney, hospital detention for assessment or treatment
- Access to services including planning for hospital discharge
- Ability to express their views about care, activities, etc.

Carers

- Getting or challenging a diagnosis
- Wanting/not wanting the person to return home from hospital
- Assessment for access to and charges for services/support
- Taking on a ‘formal role’, e.g. Power of Attorney or Guardian

The most common reason given for a social work referral was when an application for Guardianship was being made. Advocates feel that this is **far too late**. The consequences of this ‘crisis only’ referral approach is that opportunities are being missed to get to know the person and support their decision making before they lose the capacity to fully express their views. Often the person is able to express their view through body language, voice, behaviour, etc. If given more time, advocates could also gather a more holistic picture of the person and have a better informed idea of their possible preferences when they are acting on a non-instructed basis.

¹² www.olderpeoplewales.com

There is concern that Section 13ZA of the Social Work (Scotland) Act 1968¹³ (an order to move the person from their current residence under an Adults with Incapacity Act intervention) is being used inappropriately, often as an interim measure to getting a Guardianship Order in place. A 13ZA intervention can only be used once and should not be used to move the person to a place where they cannot leave; their liberty should not be restricted. Advocates feel this is often not being fully considered as forced moves under 13ZA for people with dementia are usually to a residential or nursing care environment.

In their draft guidance in response to the Cheshire West Supreme Court decision, the Mental Welfare Commission confirm that Section 13ZA cannot be used as authority for implementing a care plan where the adult does not agree with the proposed action or it appears that he/she is likely to indicate an unwillingness to remain in or agree to the care arrangements. Neither should it be used when any of the other parties involved voice an objection. In the case of an independent advocate any objections they voice should be as part of their role in representing the adult.

Advocates feel Guardianship is often used as the first option for people with dementia. There is a sense that the Adults with Incapacity Act principle of using the least restrictive option is not really considered to the same extent as it is for people with learning disabilities, for example. Advocates report having only limited success with halting Guardianship proceedings for people with dementia. They have been more successful, however, in supporting the person to influence the powers of their Guardianship.

Advocates feel that there is an over use of Guardianship and that risk-averse Local Authorities are a significant contributing factor. Risk appears to be looked at in terms of the risk to the Local Authority rather than weighing up the benefit/risk equation for the person themselves.

Statistics included in the Mental Welfare Commission's Adult with Incapacity Monitoring Reports show an increase in Guardianship orders for people with dementia from 894 in 2012/13 to 1056 in 2014/15 (an 18% rise over 3 years). The most recent report also shows an 84% increase of guardianship orders across all client groups since 2009/10.

13 <http://www.gov.scot/Resource/0045/00454245.pdf>

Similarly, the Mental Welfare Commission's report 'Guardianship Research, Analysis and Projects 2014'¹⁴ states:

“There is also a consistent trend towards greater use of formal decision making in relation to adults with age related conditions, such as dementia and Alzheimer's disease. As the population ages, the trend is likely to continue and warrants proactive assessment of the related legal, policy and service frameworks.”

¹⁴ http://www.mwcscot.org.uk/media/220997/final_report_-_guardianship_related_research_and_analysis_-_2014_final.pdf

The impact of Independent Advocacy

“Independent advocacy is a unique service. It provides a type of support they cannot find anywhere else. Advocacy has significant impacts on people’s lives through measurable outcomes (helping them access services, challenge agencies, leave a care home, etc) and also through more subtle changes in increased confidence and in regaining and maintaining control over their own lives and situations. It appears however that advocacy can remain an unknown concept for many who need it most.” (‘Advocacy is for the People – Research into the impact of independent advocacy on the lives of older people’ SIAA, 2014)¹⁵

From both our contact with people during visits to the focus areas and the advocacy stories received it is clear that independent advocacy can make a significant difference to the lives of people affected by dementia.

Some **examples** include:

One to one Professional Advocacy

- **Brian** was a carer who had recently been diagnosed with dementia, concerns had been raised about his ability to continue caring for his wife. The advocate spent time encouraging Brian to think about both his and his wife’s needs and how these could be met. They helped Brian to express his views at meetings about his wife’s care and supported him to access a carers’ assessment.

As a result of the advocacy support received Brian feels less stressed and able to continue with his caring role. Appropriate respite for Brian and support for his wife has been put in place.

Future plans were also made to ensure that Brian continued to be included and his views and wishes recorded for a time when he may require additional support.

- **Dinah** was an older person with dementia who had no family nearby and wanted to move to a different town but was finding it hard to access information and support. Dinah is hard of hearing and needed additional support to understand what was being said to her by housing officials and other professionals.

15 <http://www.siaa.org.uk/publications/advocacy-people-research-impact-independent-advocacy-lives-older-people-2/>

The advocate took time to understand what Dinah was looking for and to explore the housing options that could best meet her needs. The advocate supported Dinah throughout every stage of her move including applying for a Community Care Grant.

Dinah seemed very unsettled when she moved in to her new home and was forgetting simple things like how to work the gas meter. The advocate helped Dinah to access a tenancy support worker who spent time helping her to understand how to use the card meter.

The advocate noticed that Dinah was forgetting information and often appeared distressed and confused. She was also making daily visits to her property owner's office and calling the Citizen Advice Bureau repeatedly about the same issue.

There is concern that Dinah may be in the early stages of dementia and the advocate has supported her to go to her G.P. and is helping her to complete an assessment for Self-directed Support.

Advocacy helped Dinah to find the right housing to meet her needs, ensured that professionals in a range of agencies understood Dinah's communication support needs and helped her to make connections with a range of organisations that may be able to help, e.g. Care and Repair.

Citizen Advocacy

- **George** is an elderly man who is hard of hearing and has dementia. It can be difficult for him to communicate his thoughts and wishes to others and also to recall information.

He lives in sheltered housing and although he does have a large family most of them live abroad and his relationship with family closer to home has been a little strained.

James lives in a nearby town and was interested in connecting with someone in order to enable them to have their voice heard.

George enjoys watching football, smokes and has lots of stories about his time in the Navy. He has a great sense of humour and enjoys chatting about what's happening in the world, as well as what he has been up to.

James is also a big football fan so this has provided them with a basis upon which to build their relationship. George doesn't have access to all of the sports channels so James is going to help him to enquire about this as watching the football is really important to him.

George has recently been subject to Adult Support and Protection, for the second time, and James has been able to represent his views at meetings to ensure that he had a say in the decisions being made.

George says of James **“He is a nice young man and he takes good care of me”**. James enjoys George's sense of humour and notes that he is a very interesting gentleman with lots of stories to tell.

- **Susan** is in her early 50s. She referred herself to the advocacy organisation, gaining access through the mental health criteria, because she wanted to move from her sheltered housing accommodation in a small village back to the nearby town she grew up in. Susan has a daughter and grandchildren who live in the south of England. They visit once a year and are in touch by phone but are not on hand to sort out the day to day issues Susan encounters.

Susan worked with one of the issues based independent advocates and together they accomplished the move she wanted. She now has her own tenancy with a support package that suits her better. The advocate noted however that Susan was getting upset about her short term memory which seemed to be deteriorating. The advocate spoke to Susan about the possibility of longer term advocacy support through Citizen Advocacy.

The Citizen Advocacy Co-ordinator met Susan and they agreed that he would go ahead and find her an advocate. He also went with Susan to her GP to talk about her concerns about her memory. The GP has put Susan on a “Dementia watching brief” and will be seeing her every 4 months to take note of any changes. The GP also organised blood tests and requested a psychiatrist review of her mental health medication.

Susan has recently met her proposed citizen advocate Claire and they are getting to know each other. They share a love of crafts and they are both busy knitting cardigans for a premature baby unit. Susan is still concerned about her memory and her advocate is supporting her to look at making decisions now and for the future. If the time comes when Susan cannot make a decision

for herself, Claire hopes she will have a good sense of what Susan values and what she would want to happen.

Collective Advocacy

A Relatives' Advocacy Group – for people in advanced stages of dementia in two long term hospital care wards.

This group met once a month and was supported by a collective advocacy group worker from the local advocacy organisation. (It is worth noting that this support is no longer available as the collective advocacy worker's post was lost in a restructure by the local authority of advocacy provision in the region.) The group was focused on the needs of the people with dementia and the quality of their lives in the ward.

The relatives group brought a number of issues to the staff, mainly around the quality of the environment along with specific issues around staffing. Senior Ward Staff and the Mental Health Manager attended for part of each meeting and along with dealing with any issues kept the group up to date with any developments they felt might affect their relatives. A representative from the group also attended the monthly Mental Health Stakeholder meetings for that locality.

The role of this group in safeguarding their relatives and the value of independent advocacy support can be demonstrated by their success in preventing the move of the two dementia wards from the main hospital to an isolated unit in a nearby facility due for closure.

The ward staff were sure that this would not be appropriate for the people they cared for but were limited in their actions by their role and their employment. The advocate however was able to support the relatives to take a very strong proactive approach that included representation at a high level to the Health Board, the support of local Councillors and MPs and prepared press releases.

Tea and Chat sessions in an older peoples care home – (again not available as collective advocacy support was lost, as above)

This was a limited term initiative between the care home and the local advocacy organisation. The care home manager was concerned that their residents with more advanced dementia were not really joining in with the discussions about new

menus and the daily activities.

The advocacy organisation trained and supported two volunteer advocates with personal experience of caring for or supporting people with dementia to run tea and chat sessions in the care home once a week for 8 weeks. Six residents attended every week and a further two came in and out of the sessions. The table was set for high tea, with a table cloth, full array of china and a cake stand. Small taster samples of different foods were on the table at each session along with tea/coffee and a small selection of cakes. The sessions ended with a different activity each week.

The advocates took photos during each session of the table set for tea with the sample foods and each of the different activities that were offered. Discussion on the food came naturally as residents and advocates sat down to tea and a general chat. The activity not only gave residents a chance to experience new things but also signified that the session was coming to an end preparing residents for going back into the general lounge area.

When the sessions came to a close staff continued to use this kind of format to talk to residents about the home generally and later on in the year prepared a photo album to support each resident to give their views on their personal care. The home won a national community care award for the tea and chat sessions.

Access to Independent Advocacy and How This Could be Improved

Challenges and Barriers

In addition to the issues raised in relation to accessibility in section 3 above, there was a general consensus amongst both advocacy organisations and their NHS/LA commissioners that the main limiting factor is the resources available. There is an increasing sense that independent advocacy is being 'spread too thin'.

“Currently people with dementia are not always able to access independent advocacy in every Local Authority area. There is very little independent advocacy provision for carers of people with dementia. We know that even in the areas where there is provision of independent advocacy people with dementia might not be able to access it in a timely fashion. People with dementia often require more intensive, long term input from advocacy, we know that that isn't something that all advocacy organisations can provide due to the increasing demand. The Mental Welfare Commission's report on dementia wards describes how in some areas patients have access to advocacy whereas in other areas advocates are not seen on wards for months.

Independent advocacy helps people to know and understand their rights, access the services they need and ensure their voices are heard.

Local Authority and NHS advocacy commissioners and Integrated Joint Boards need to ensure that they are commissioning and properly funding independent advocacy for people with dementia and their carers. They also need to ensure that there is provision for collective advocacy. There are still too many people who don't know what advocacy is and the difference it can make.”

(Shaben Begum MBE, Director, Scottish Independent Advocacy Alliance)

Resource constraints and eligibility criteria contained in Service Level Agreements have focused advocacy organisations on prioritising people under formal measures. Wider access to independent advocacy, as detailed in legislation, has diminished and advocates are less likely to have a regular presence in long term care environments. Where links do remain referrals from staff are appropriate and made with confidence. With regular contact advocates become known to residents and their families and have a sense of life in the care/nursing environment. This is

really important especially where the advocacy is on a non-instructed basis.

“People with dementia, particularly in the advanced stages rarely have the cognitive skills to make a referral themselves. They are often dependant on professionals or family members to make a referral on their behalf despite the advocacy potentially not being in the referrers best interests.”

(Survey response from an Advocacy Commissioner)

“Independent advocacy has a central role in play in promoting people’s safety and security without compromising their personal autonomy through supporting decision-making and communication, removing the undue interference of others and in enabling individuals to recognise the strengths and weakness, opportunities and threats of different options available to them.”

(‘From Safety net to Springboard’, Equality and Human Rights Commission, 2009)¹⁶

The opportunity cost of prioritising those under compulsory measures, important as this is, is that people in the earlier stages of their dementia are often not able to call on advocacy support to get their views taken into account in planning for their futures. Where individual advocacy support has been available earlier on, the advocates feel they made a real difference. They felt some of the people they supported were able to stay at home longer because their care was better tailored to the person’s own preferences and when they did have to move into long term care, this was managed in a calmer, more considered way - not as a crisis. All too often the preventative possibilities of advocacy support are being missed.

“The Commission is aware that there is a lack of access to advocacy services for many people with dementia, despite the duty on health boards and local authorities under the Mental Health (Care & Treatment) Act 2003 to make independent advocacy services available to them.

Under the 2015 Mental Health Act there is a new duty on health boards and local authorities to provide the Commission with information on how they have been ensuring the availability of advocacy services, and what their plans are for future provision. This new duty comes into effect in April 2017, and we will be asking specifically about how their strategies provide for advocacy for people with dementia. Access to advocacy is important for people whether or not they are subject to compulsory measures, and is central to ensuring that people are afforded their rights.”

(Mental Welfare Commission)

¹⁶ <https://www.equalityhumanrights.com/en/care-and-support/guidance-care-quality-commission-inspectors/report-safety-net-springboard>

Whilst the role of advocacy organisations is focused wholly on the individual they are advocating for the following example of a citizen advocacy partnership also demonstrates the potential benefits to statutory organisations responsible for meeting someone's social care needs.

David is now in his mid- sixties. He has a learning disability and more recently, dementia. David spent his earlier years in a large institution for people with learning disabilities. He has no close family or friends able to support him.

When the hospital closed down he was placed in supported accommodation which worked very well for him. When the provider changed however David found himself sharing his flat with a much younger man who was facing some difficult life challenges. Both David and his new flat mate were stressed by the new arrangements and David's distress resulted in changes in his behaviour.

A staff member contacted the advocacy organisation because she had heard about citizen advocacy in a Women's Institute meeting. The Citizen Advocacy Co-ordinator, Christina, came out to meet David that week. She spent about two months getting to know David so that she could search for the right advocate to support him. She also started to help him think about what was happening in his life and what he might like to do about the issues he was facing.

David was introduced to John, a retired teacher, with similar interests. Both enjoy football, especially following the local team and they share a love of home baked cakes and coffee shops. The advocacy partnership has been going for over two years now and David has John's support in making significant changes in his life.

David moved away from his former provider and now lives in his own tenancy with support bought in from a local care organisation. His care team have listened to him and with John's help they have supported him to make his home the way he likes it; calm, clean, smoke free and warm.

David likes to get out every day but his mobility is declining. John and the staff team are now looking at applying for mobility benefit which would enable him to have a car for his own use. John will also be helping David understand and cope with proposed changes in his care team. David no longer has over-night care and his support costs less overall than his former package.

Advocacy organisations, commissioners, people affected by dementia and other stakeholders were asked about any challenges and barriers which could have an impact on accessibility. In addition to the challenge of limited resources available outlined above, the main themes included:

- Patchy awareness and understanding about independent advocacy
- Social work referrals being made primarily at the point of crisis
- A significant gap in relation to independent advocacy for carers
- Communication or cognitive impairments caused by the dementia itself including the person's ability to instruct an advocate
- Concern across stakeholder groups about advocates' knowledge and understanding about dementia
- The stigma and fear associated with dementia
- People living in remote or rural communities
- Language - both for people who use British Sign Language and people whose first language isn't English and may revert back to Gaelic, for example, as their dementia progresses
- The view "they don't know or can't say what they want so why would they need an advocate?" continues to be all too common
- Family members objecting to the involvement of advocacy – this can be exacerbated if the family member has Power of Attorney, in particular where information about the specific powers included are not readily available

Another significant factor was the perceived lack of oversight in relation to independent advocacy planning by NHS Boards and local authorities since the demise of the Advocacy Safeguards Agency. Both advocacy organisations and commissioners welcome Amendment 29 to the Mental Health Act requiring NHS Boards and local authorities to provide information to the Mental Welfare Commission about how they have discharged their duty to ensure that people with mental health problems (including dementia), whether or not subject to compulsory measures have access to independent advocacy.

Improving Access and Giving People Affected by Dementia a Stronger Voice

Unsurprisingly the most common suggestion with regard to improving accessibility was increased investment in independent advocacy provision.

Other suggestions included:

- Persistent promotion of independent advocacy at a National level by the Scottish Government, SIAA and other relevant agencies.
- Awareness raising and training about independent advocacy for key health and social care staff including clear information about the potential role and value of independent advocacy for people at various stages of their dementia journey. Also the potential benefits to professionals, e.g. a clearer understanding of the person's views and wishes, support packages with a greater chance of success as the person has played a full role in deciding how their needs will be met.
- Local awareness raising activity and materials targeted specifically at people affected by dementia.
- Specialist dementia training for advocates.
- Health and social care staff playing a proactive role in referring or signposting people with dementia at key points in the dementia journey, e.g. at the point of diagnosis, during Self-directed Support assessments or reviews and at other times when decisions which will affect their lives are being made, especially where there are conflicting views.

“I would expect the staff using the (Alzheimer Scotland) five or eight pillars model to be informing people with dementia and carers about independent advocacy and how to access it.” (Survey response from a voluntary organisation)

- More independent advocacy available to people from minority groups.

- Clearer systems for recording unmet needs (specific to dementia), including people on advocacy waiting lists as well as people who do not meet existing eligibility criteria. This information will help advocacy organisations and commissioners to plan and also to make the business case for increased investment where needed. A supplementary question was asked with regard to what would give people affected by dementia a stronger voice. This was in recognition of the fact that whilst independent advocacy has a key role to play it is not the answer on its own. In addition to this, an important aim for all independent advocacy is to support and encourage people to speak up for themselves wherever possible. The main suggestions with regard to giving people a stronger voice were:
- Making sure people have access to information, in appropriate formats, about the range of support available and their rights, for example to high quality health and social care.
- Increasing public awareness about dementia and reducing the stigma related to it.
- Support services planned in a person-centred way.
- More education for people with dementia and carers about living well with dementia and about formal roles, e.g. Power of Attorney, Guardianship etc.
- Greater use of advance statements and similar planning tools.
- More awareness by professionals about the pressures on carers, e.g. consulting them during discharge planning - can they cope? What support do they have/need? The Carers (Scotland) Bill passed by the Scottish Parliament on 4 February 2016 introduces several new duties which should help with this.
- Increased collective advocacy for people affected by dementia.
- And the importance of ‘Having a seat at the table as an equal partner – not just being talked about, but included’.
(quote from a stakeholder)

Priorities for Access to Independent Advocacy

“Independent advocacy is particularly important in certain circumstances including older people’s entry into care homes or when facing major decisions and changes to their lives.”

“There is a strong case for an independent advocacy process where advocates acting on behalf of patients, families and carers would challenge what is all too often seen as an automatic pathway into residential care at a time when an individual older person is experiencing a significant dip in their physical, mental and emotional health.”

(Voice, Choice and Control, Older People’s Commissioner for Wales, 2012)¹⁷

There were a number of similarities between the priorities identified by advocacy organisations, commissioners and other stakeholders. Those that all groups agreed on were:

- At the point of diagnosis
- Where there are conflicting views with regard to diagnosis, care and support needs and how they should be met, whether the person with dementia can remain at home, return from hospital, etc.
- When formal measures are being considered to deal with financial planning, e.g. Power of Attorney or where care homes are authorised to manage a resident’s daily money
- Where compulsory powers are being considered under mental health or adults with incapacity legislation
- At (and in preparation for) formal meetings including assessments, reviews, especially where there are proposed changes to the level or type of support provided
- At times of transition, e.g. accessing services or becoming a carer for the first time, moving from adult to older people services or moving from home in to long term care

17 www.olderpeoplewales.com

Other suggested ‘triggers’ for referral were:

- People living in isolated situations or who have no-one to speak up for them
- Making a complaint
- Where carers considering taking on formal roles, e.g. Power of Attorney, Guardianship

“In the UK there was widespread agreement between lay proxies and professionals that the heavy demands on lay proxies go largely unrecognised and they receive little information, advice and support. There is no statutory duty for lay proxies to be offered training, yet they are required to comply with principles and duties set out in Codes of Practice, of which few are aware.”

(‘Dementia: Autonomy and Decision-making – Putting Principles in to Practice’, Alzheimer Scotland, 2012)

- When the person finds it difficult to communicate/negotiate with ‘the system’
- The person with dementia or carer in crisis
- Planning end of life care

Supporting Independent Advocacy for People Affected by Dementia

The SIAA produced 'Principles and Standards for Independent Advocacy' in 2008. These along with the associated Code of Practice underpin the work of advocates and advocacy organisations.

Principle 1: Independent advocacy puts the people who use it first.

- Standard 1.1: Independent advocacy is directed by the needs, interests, views and wishes of the people who use it
- Standard 1.2: Independent advocacy helps people to have control over their lives and to be fully involved in decisions which affect them
- Standard 1.3: Independent advocacy tries to make sure that people's rights are protected
- Standard 1.4: Independent advocacy values the people who use it and always treats people with dignity and respect

Principle 2: Independent advocacy is accountable

- Standard 2.1: Independent advocacy is accountable to the people who use it
- Standard 2.2: Independent advocacy is accountable under law
- Standard 2.3: Independent advocacy is effectively managed

Principle 3: Independent advocacy is as free as it can be from conflicts of interest

- Standard 3.1: Independent advocacy cannot be controlled by a service provider
- Standard 3.2: Independent advocacy and promoting independent advocacy are the only things that independent advocacy organisations do
- Standard 3.3: Independent advocacy looks out for and minimises conflicts of interest.

Where an independent advocacy organisation provides advocacy to both the person with dementia and their carers it is important that effective processes are in place to minimise conflicts of interests. This should include the person with dementia and their carer having different advocates and ensuring that information isn't shared between these advocates without consent.

Principle 4: Independent advocacy is accessible

- Standard 4.1: Independent advocacy reaches out to the widest possible range of people, regardless of ability or life circumstance.

The reason Independence is so crucial is that whilst many people providing health and social care services do their best to safeguard and empower people they often have to manage limited resources and have professional responsibilities which present a conflict of interests. It can also be difficult for them to be critical of services that they or their organisations deliver.

We asked both advocacy organisations and their commissioners about any further guidance, policy or training they would like to see:

Advocacy Organisations	Commissioners
Training for advocates similar to the Advocacy and Stroke Training produced by the Stroke Association and SIAA	Training for Care Managers on the role and benefits of independent advocacy
Guidance and tools to improve communication with/for people with dementia	Generic leaflets about independent advocacy suitable for professionals and individuals as well as a National advertising campaign
Training to support people with dementia, carers and professionals to understand independent advocacy's role in getting the views and encouraging the participation of people with dementia	Policy and guidance as this is often the driver for Local authorities to take action, particularly in times of austerity when councils are traditionally scaling back on services rather than increasing them. The new duties for the Mental Welfare Commission could play a useful role here.

Advocacy Organisations	Commissioners
Non-instructed advocacy training for advocates including guidance on giving the client's views when dementia is an issue and credibility may be questioned.	Induction training about Independent Advocacy for all NHS/Local Authority front line staff – the Mental Welfare Commission could include reporting on this as part of their new role in relation to independent advocacy planning
An information resource and/or training about relevant legislation (e.g. Mental Health, Adult with Incapacity, Adult Support and protection) designed specifically for advocates	More effective monitoring of access to Independent Advocacy
A Dementia Advocacy Forum similar to the Prison Advocacy Forum which provides opportunities to share information and discuss common practice issues.	
More effective monitoring of access to Independent Advocacy	

An important element of the advocate's role is to help people understand what their rights are including what support and services they should expect to receive. Two key documents are 'Scotland's Dementia Strategy' and 'The Standards of Care for Dementia in Scotland'.

The Standards of Care for Dementia in Scotland¹⁸ give people with dementia the right to:

- A diagnosis
- Be regarded as a unique individual – treated with respect and dignity
- Access a range of treatments, care and support
- Be as independent as possible and included in your community
- Have carers who are well supported and educated about dementia
- End of life care that respects your wishes

Scotland's Dementia Strategy 2013/16¹⁹ includes the following Key outcomes:

- More people with dementia living good quality of lives at home for longer
- Dementia friendly/enabled communities – increased awareness and reduced stigma
- Timely, accurate diagnosis
- Better post diagnosis support
- More people with dementia, families/carers involved as equal partners – throughout the dementia journey
- Better respect and promotion of rights in all settings – improved compliance with legal requirements with regard to treatment
- People with dementia in hospitals or other institutional settings are always treated with dignity and respect

We asked advocacy organisations and other stakeholders about their knowledge of these documents and their experience with regard to how they were working in practice.

18 <http://www.gov.scot/Publications/2011/05/31085414/0>

19 <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>

Both groups felt that the strategy provided a valuable framework but they were concerned that implementation had been slow and variable. They were also concerned about whether there were adequate resources to enable the strategy and standards to move from being aspirational to reflect the support and services people can realistically expect to receive.

“I think a lot of the strategy is excellent in principle but it isn’t always translating in to practice.”

(Voluntary Organisation)

“Aspirations are always important but how these translate at a local level can be varied due to a wide range of influencing factors.”

(Advocacy Organisation)

Other issues raised:

Advocacy Organisations

There was significant variation with regard to knowledge about these – an important factor being time pressures and the balance between keeping pace with the demand for advocacy and remaining informed about changes or developments in national policies.

Some have made good use of these on an individual or collective basis to inform people of their rights. Also to demonstrate the experience of people affected by dementia, in particular where this has fallen short of the expectations contained in the strategy and standards.

“We have made reference to them in our practice, for example in review meetings in care homes, e.g. the person’s right to take part in their community.”

Some advocacy organisations are involved in local dementia strategy/ planning groups and have been able to raise awareness about the role and value of independent advocacy.

There was a sense that the strategy has resulted in good support or services at crisis points but that earlier support is needed to help people affected by dementia to plan for their future.

Specific areas of concern included:

- The demand for post diagnostic support outstrips supply in some areas leading to waiting lists
- Conflicting information about housing or care options available
- Limited support available to help people plan palliative care and a lack information about available resources. This can leave people feeling lost and alone during this final portion of their life.
- The effective involvement of people affected by dementia:

“It would have been exceptionally valuable to include the provision of independent advocacy as part of the strategy at a rights based level and again under commitment 14 (Integration Outcomes) as we have seen limited local consultation on Health and Social Care Integration. As a consequence, it is likely to be that there has been limited input from those who are coping with dementia.”

- Concern with regard to people who develop dementia but are already receiving support for another reason, e.g. learning disability.

“In our experience there is little or no change to the care and support package when dementia is added to the diagnosis of someone with a learning disability.”

Other Stakeholders

Similar to advocacy organisations many of the other stakeholders had made use of the strategy and standards to let people know what they should expect from support and services:

“We welcomed the fact that it takes a rights based approach to the delivery of support and services to people with dementia ... it sets out their rights to diagnosis, support services, community connections and a whole range of areas when agencies have a duty to make the right provision for people with dementia.”
(Voluntary Organisation)

There were concerns around how familiar front line staff and the public are likely to be with the strategy or standards:

“The standards are great but I’ve heard of a few cases where carers have referred to them when trying to access services and they haven’t always been recognised by NHS or local authority staff.”

(Voluntary Organisation)

There was also recognition of the need to ensure that there were effective plans and opportunities for people affected by dementia to be as involved as they would like to be in the development/review of a broad range of national policies, etc. not just those which relate specifically to dementia.

Conclusions

Whilst this exploratory study has been brief there was widespread agreement that independent advocacy has been and could be valuable for people affected by dementia at all stages of their 'journey'. For example, introducing advocacy to people:

- **During the early stages of their dementia** - at or around the time of diagnosis or assessment can help them to understand how the condition may affect them and begin to consider the options available for services and support. Advocacy provided at this stage can help people to plan ahead and ensure a better quality of life. Even where involvement of an advocate at this stage is relatively short term it brings the added benefit of providing a connection with advocacy which may help people to feel confident about seeking advocacy input again as and when new issues arise.
- **Considering/accessing services for the first time** - can help to ensure that people have all the information they need to make an informed choice. This is likely to include ensuring they understand what their rights are, helping them to 'research' the options available and enabling them to put forwards their 'case' for support that best meets their needs and wishes.
- **At times of transition** - for example where decisions are being made about long term care. Advocacy provided at this stage can ensure that, where people would prefer to stay in their own home, every effort is made to support them to live independently. This is particularly important where there are conflicting views or where it appears that principles underpinning legislation, e.g. the least restrictive option, haven't been adhered to. Where a decision is made for someone to enter long term care advocacy can also help the person to ensure their voice is heard in relation to the facility best suited to them.
- **When compulsory powers or formal roles are being considered** - for example where a local authority or family member is applying for Guardianship. Independent advocacy can help the person, if they wish, to challenge whether the conditions for the order have been met and to inform the powers that will be included. Advocacy can also support carers to consider whether they are willing to take on a formal role e.g. Power of Attorney.

- **Planning end of life care** - ideally people will have had support (including independent advocacy) and opportunities to do this throughout their dementia 'journey'. Where this hasn't happened independent advocacy can play a crucial role in ensuring that the person's past and present views are taken in to account. Where the person has very limited communication skills and the advocate is unable to get clear information from them the advocate will speak to people who have known them well to build a picture of what their wishes have been in the past.

We have seen examples of a range of advocacy approaches (one to one issue based, citizen and collective) and believe that all of these have a valuable role to play for people affected by dementia. Given the nature of the condition we believe that there would be particular advantages to ensuring people with dementia have access to independent advocacy at or round the point of diagnosis and/or citizen/ longer term advocacy. Both of these provide opportunities to build relationships at a point where people are most likely to be able to engage fully in deciding what care and support would be acceptable to and appropriate for them.

“Older people might require different forms or types of advocacy at different times and might even benefit from using more than one at the same time.” (‘A Scoping Study of Advocacy with Older People in Wales’, Andrew Dunning for the Older People’s Commissioner for Wales, 2010)²⁰

This study has also reinforced concerns that there are significant barriers to people affected by dementia accessing independent advocacy. This reflects the findings included in **SIAA’s 2014 Advocacy Map**:

“We asked advocacy organisations if their Service Level Agreement or Contract did require them to prioritise those facing compulsory measures and if so, what impact this had on advocacy availability.

50% of organisations that have Service Level Agreements or Contracts stated that they are now required to prioritise those individuals facing compulsory measures. Of that group over half now have waiting lists and state that the wait for advocacy can be significantly longer for individuals not subject to compulsory measures. Around 20% of that group reported that they had now stopped offering ‘drop in’ or ‘surgery’ sessions and over 40% no longer undertake any awareness raising activities.

²⁰ www.olderpeoplewales.com

It is likely that the reduction in awareness raising activities and longer wait for access will contribute overall to reduced accessibility for all. We are concerned that some who do have a statutory right of access and could benefit from advocacy are not likely to find out about it if organisations feel unable to raise awareness or reach out to the harder to reach people.”

Whilst the greatest barrier is the level of resources available to independent advocacy organisations coupled with the need to prioritise people subject to compulsory powers, a number of other factors also play an important part. In particular:

The absence of a dementia ‘badge’ – as people with dementia’s right to access independent advocacy is enshrined in mental health legislation the eligibility criteria included in, for example, the SIAA web based directory and in advocacy organisation’s own publicity materials often does not identify dementia specifically but includes it under the umbrella term of mental health. However, people with dementia don’t necessarily identify themselves as having a mental health problem and therefore may not recognise that independent advocacy is available to them.

An important finding of an Independent Advocacy and Stroke Project carried out by the Stroke Association was that whilst many of the people who accessed one of the Stroke Advocacy Pilot Projects would have been eligible under another criteria, e.g. mental health or older people they didn’t automatically recognise it as something that was relevant or accessible to them. The targeted awareness raising specific to stroke including posters and leaflets as well as making connections with the services they were likely to be using such as hospital and community rehabilitation teams was invaluable.

The limited independent advocacy available for carers – the information contained on the SIAA website includes only 10 local authority areas which specifically mentioned offering independent advocacy for carers. We recognise that some carers can, and indeed do, access independent advocacy either through organisations that are available to everyone (1 local authority area) or through other eligibility criteria such as older people or mental health. However, this is unlikely to be applicable to everyone who may be caring for a person with dementia.

Patchy awareness and understanding of independent advocacy – this was an area of concern in relation to people affected by dementia and the wider public as well as the broad range of agencies and professional who may have a role to play in referring or signposting people to advocacy organisations.

“The principles of advocacy were partly understood by care home managers and staff. They tended, however, to place emphasis on advocacy as a method of safeguarding and protection, dealing with complaints and dispute resolution. There was also a common belief that advocacy was primarily for people with dementia who were unable to express their own views and wishes or those with little or no close family involvement.”

“Front line staff care staff are vital in promoting and helping residents to access independent advocacy. It is imperative that they have a sound understanding of its role and purpose as well as the scale of local provision and how it can be accessed.” (‘Voice, Choice and Control’, Older People’s Commissioner for Wales, 2012)

There has been significant headway made with regard to independent advocacy for people with mental health issues since the implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003. Where compulsory powers are being sought people are routinely referred to independent advocacy and the absence of independent advocacy is recognised as a cause for concern in Tribunal hearings. The same awareness and understanding of independent advocacy does not appear to be present out with specialist teams such as Community Mental Health Teams.

“It is interesting that with the huge and highly publicised investment that there has been in dementia awareness for the public and dementia education for health and social care staff over the last ten years that the role of advocacy for vulnerable adults with dementia is so underdeveloped. Perhaps we have been given the impression that there are organisations and champions in large numbers who fulfil this role, trained and ready for action, but this research shows that this is not the case. Expectation has been created and the impression that there will be help is cruelly dispelled when you have personal experience of struggling with the system, or witness the deprivation of liberty that is still common for people with dementia.” (Professor June Andrews, Dementia Services Development Centre)

Another important factor is the all too common view that the nature of dementia, particularly for those who are seen to lack capacity or whose verbal communication skills are impaired, makes independent advocacy irrelevant or unnecessary. This highlights the importance of information and education about dementia that challenges the stigma associated with it, encourages people to recognise that a diagnosis of dementia doesn’t automatically mean that someone is incapable of making decisions or playing a full part in planning the care and support that will best meet their needs and provides them with the skills and confidence to support people to

live well with their dementia.

We also heard from a number of NHS and local authority stakeholders that independent advocacy had ‘dropped off’ of the induction training programmes for new staff due to other demands in relation to what needs to be covered alongside the capacity of advocacy organisations to take on this role.

We heard repeatedly that independent advocacy organisations had to reduce the amount of awareness raising activity they were carrying out as they didn’t have the capacity to respond to any significant increases in demand. This is something of a double edged sword as advocacy organisations try to walk a very difficult line between not generating more demand for advocacy than they can respond to whilst keeping waiting lists at a manageable level and demonstrating the ‘business case’ for increased resources.

In addition to this we heard examples of Service Level Agreements with advocacy organisations that appeared to restrict their activity to ‘hands on’ advocacy only. The resources needed to raise awareness about the role and value of independent advocacy, be visible in dementia wards or care homes for example or to participate in local strategy development or networking activities are not included and therefore need to either be cut or funded from charitable trusts, etc.

This reduced ‘visibility’ coupled with the pressure to prioritise people subject to compulsory powers has led to a reduction in the safeguarding role that independent advocacy organisations can take on. This role is crucial in protecting the rights of people with dementia when they are at their most vulnerable. An example of this could be someone in a long term care setting who either has very limited verbal communication skills or who, for whatever reason, rarely expresses their views or wishes about the care and support they receive. By having a regular presence advocates become familiar to both people affected by dementia and the staff responsible for the care provided. This can enable them to pick up on potential advocacy issues in a more informal way and provides easy opportunities for people to make referrals.

Language barriers – these may relate to the impact of the dementia itself, reducing their ability to express their views or understand what others are saying. For people whose first language isn’t English it may be that they revert to Gaelic for example as their dementia progresses. Similarly, the barriers may be unrelated to their dementia; they could rely on British Sign Language or be from another country and not speak English.

It is important that advocates are provided with the skills and resources necessary, e.g. communication aids and interpreting services to allow them to carry out their role effectively and to enable people affected by dementia to have their voices heard.

An important factor in all of this is recognition that it takes time to build relationships and to ensure that the person has the best possible chance of having their voice heard. We heard from a range of stakeholders that they valued the fact that advocates were often able to commit more time to people with dementia than other professionals, e.g. care managers and others carrying out assessments for Self-directed Support. However, we also know that the resources available to advocacy organisations are limited whilst demand for independent advocacy is growing. It will therefore be important that advocacy commissioners take this in to account when developing their local independent advocacy plans and Service Level Agreements with advocacy organisations.

The Skills and Confidence of Advocates – whilst there is a significant amount of experience across Scotland of advocating for people affected by dementia there was a strong sense from advocacy organisations, commissioners and other stakeholders that specific dementia training for advocates would be helpful.

The Advocacy and Stroke Training produced and delivered for the Stroke Association in partnership with SIAA would provide a useful model for this. It provided a one-day training programme which combined basic information about stroke and the impact it can have on stroke survivors and their carers (including links to other resources such as the range of Fact Sheets produced by the Stroke Association), tools and approaches for communicating with people experiencing aphasia, etc, with practice based sessions focussing on the type of advocacy issues stroke survivors might face and how to work with them to address these.

An invaluable element was the involvement of stroke survivors and carers in the design and delivery of this training. The feedback from training participants time and again was that this was the most valuable and memorable part of the training. In particular, the opportunity to hear their personal stories and to ask questions about them and having their involvement in the training exercises and discussions throughout the training session.

Advocacy organisations have used these materials to roll out training to their own staff and volunteers as well as in training and awareness raising for other people and organisations in their communities.

We feel it will be important that any Advocacy and Dementia Training developed covers relevant legislation and National policies, therefore it is unlikely that a one-day training programme would be adequate.

This report will, we hope, be a starting point to considering the better and more effective use of independent advocacy in Scotland. We believe that there is much that the Life Changes Trust and other key organisations, e.g. the Mental Welfare Commission and the SIAA, could do to promote the use of advocacy. We must secure a stronger voice for those who are unable to speak for themselves.

Appendix 1 Research Team Members

Charlotte Lee

Charlotte has been involved in independent advocacy across Scotland for about twenty years. This has involved establishing and managing an independent advocacy organisation for people with dementia, leading on the development and implementation of Scottish Government guidance on commissioning advocacy, providing development support to advocacy organisations and commissioners as well as carrying out a number of independent evaluations of advocacy organisations.

In recent years Karen Irvine and Charlotte have worked together on national development projects around advocacy and stroke, advocacy and self-directed support and quality assurance for independent advocacy organisations. These roles have involved engaging with a broad range of stakeholder groups including advocacy organisations, service users and carers, NHS and local authority staff, Scottish Government, national and local voluntary organisations. Important elements of these projects have been identifying areas of good practice that can be shared across the advocacy movement, gaps and areas for development or improvement along with the barriers and challenges faced.

Karen Irvine

Karen Irvine has over 25 years of experience in supporting people to have a stronger voice and secure their influence in shaping their own futures. Karen works mainly with people whose lives have been affected by health or social inequalities and are facing difficult challenges. Her experience includes delivering and managing independent advocacy at a local level and supporting the strategic development of independent advocacy nationally across a number of projects.

Karen has an arts background and an interest in developing approaches which support people with additional communication needs to voice their views. This includes producing a tool kit for enabling people with dementia to give their views on their care during regulatory visits, supporting service users to devise an information strategy for a local authority homelessness service and supporting a peer evaluation of advocacy for people affected by stroke.

Charlotte Lee and Karen often work together and have an established reputation, individually and as a team, for taking a sensitive inclusive approach, producing well researched findings and suggesting achievable development recommendations.

Amanda Scott

Amanda has a BSc (Hons) in Complementary Medicine and Health Sciences. After declining the offer of staying on at university to undertake more research, Amanda went on to become a Registered General Nurse undertaking a Shortened Course for Graduates at Napier University and gaining a Diploma in Adult Nursing. Previous to this Amanda completed a Diploma in Health and Holistic Therapies and was a massage therapist and reflexologist until she became more interested in research and the underlying reasons for ill health.

After taking a career break Amanda decided to resume her career in health and started nursing again before being employed by Carr Gomm, Community Contacts in January 2014 as a part time Community Project Worker in a Self-Directed Support Project

Amanda also worked for MECOPP (Minority and Ethnic Careers of People Project) in the Gypsy/Traveller Project for six months carrying out development work. This involved information gathering for Gypsy/Traveller Community members as well as delivering awareness raising training to professional on Traveller issues.

Amanda is committed to Human and Women's Rights, and enjoys research whilst taking a very person centred approach. Her favourite things are listening to people's stories - qualitative research- and identifying themes and traits.

Christina Wallace

Christina has a Diploma in Health Related Studies gained from Robert Gordon University after studying Occupational Therapy. Through-out her in-class studies and course practical placements (based in physical and mental health settings) she gathered a real understanding and appreciation of the value of person-centred, holistic care, being a voice for clients who may otherwise be ignored or assumed to require no further treatment and the importance of advocacy services in a variety of settings. This was further developed through her own employment within care homes, working both in an advanced-stage dementia specialist care home wing

and a care home based on varied care requirements and conditions living together. Beyond this Christina has personally been involved in care and treatment meetings with her own family members and has, along with other family members, helped support the wishes of the person to medical professionals.

Christina is currently on a career break, having become based within administration in the oil and gas industry, to raise her child. However she has recently passed the PEEP (Parents Early Education Partnership) toddler development unit at level 4.

Appendix 2 Relevant Policy and Legislation

Mental Health (Care and Treatment) (Scotland) Act 2003 states that “Every person with a mental disorder shall have a right of access to Independent Advocacy”. This includes people with dementia.

Adults with Incapacity (Scotland) Act 2000 as amended by the Adult Support and Protection (Scotland) Act 2007, states “In determining an application or any other proceedings under this Act the sheriff shall ... take account of the wishes and feelings of the adult who is the subject of the application or proceedings so far as they are expressed by a person providing independent advocacy services.”

Adult Support & Protection (Scotland) Act 2007 places a duty on Local Authorities “...to consider the importance of providing advocacy and other services”.

Patient Rights (Scotland) Act 2011 places a duty on Patient Rights Officers to signpost individuals to “(ii) persons providing representation and advocacy services.”

Social Care (Self-directed Support) (Scotland) Act 2013 places a duty on Local Authorities to provide “...in any case where the authority considers it appropriate to do so, information about persons who provide independent advocacy services

The Standards of Care for Dementia in Scotland states that “the standards are based on your rights. You should use them to get the care, treatment and support you need. If you think the standards are not being met, there are a number of things you can do:

- You can quote the standards when making a complaint to the care provider.
- You can get help from independent advocacy or Citizens’ Advice when
- making a complaint.”

The National Care Standards: Standard 19. “You have access to other agencies and services, such as advocacy, that can support you in making your needs and preferences known. They can, with your permission, represent you and give your views. Information on these services is provided in a way you can understand.”

The Keys to Life - Improving quality of life for people with learning disabilities (2013) This policy recognises that advocacy provision is patchy across Scotland. It states that “Not everyone will need or want an advocate but, as the Joint Committee on Human Rights report on the human rights of adults with learning disabilities highlighted, it is of particular value to people with profound and multiple disabilities.”

Caring Together: The Carers’ Strategy for Scotland (2010-2015). This strategy confirms the importance and value of advocacy for carers in their own right and encourages support for the development of carer advocacy.

Standards of Care for Dementia in Scotland (2011) - Promotes the importance of access to independent advocacy.

While these emphasise the importance of advocacy and recognise that providing access to advocacy is good practice they fall short of ensuring that all those who need it are receiving it.





Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways:

Phone: 0141 212 9600

Email: enquiries@lifechangestrust.org.uk

Website: www.lifechangestrust.org.uk

Address: Life Changes Trust, Edward House,
283 West Campbell Street, Glasgow,
G2 4TT