Taking their side: fighting their corner

16 stories demonstrating the difference independent advocacy makes to the lives of people with dementia

dementia advocacy network

advocacy plus
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DAN is a national support network for advocates working with people with dementia. It began in 2001 and grew out of the work of the advocacy service provided by Westminster Advocacy Service for Senior Residents (now known as Advocacy Plus). It now has 250 members. DAN provides networking and training events, promotes best practice in advocacy and campaigns for increased access to independent advocacy for people with dementia.

The Dementia Advocacy Network is an arm of Advocacy Plus London Ltd, a registered charity that works to improve access to advocacy for all older people.

www.advocacyplus.org.uk/dan
When our organisation was set up in 1993 as Westminster Advocacy Service for Senior Residents, our principal purpose was to provide advocacy services for older people in the borough. We soon came to recognise our need for the specific skills required for working with our clients who had dementia. From an early stage therefore, we set out to recruit specialists with forensic knowledge of dementia and experience of advocating on behalf of people with dementia. We soon found that these individuals did not exist in any numbers.

If our work was to be of value to our clients with dementia, we knew our service needed to support them throughout their journey, from onset to the end of their lives. We started a training programme for our staff and volunteers so they could work with clients with dementia. The success of this programme, which was unique and ground breaking in many ways, helped us considerably in our client service and became widely known and respected.

Once our expertise became known outside the City of Westminster, we found that we were contacted by advocacy professionals across the country looking for support and advice in how to address the many issues faced by advocates when working with people with dementia. We discovered that there was no support system for them. As a result we decided to form the Dementia Advocacy Network (DAN).

DAN is a support organisation disseminating best practice for professional advocates working with people with dementia throughout the country. We provide a forum to discuss issues affecting our members and training for a wide range of staff and volunteers. The DAN membership is drawn from right across the country (from Cornwall to Northumberland) and such is the reputation of Advocacy Plus that staff have been asked to promote our work as far afield as Russia and Germany.

DAN is an essential part of Advocacy Plus, both providing the support that is necessary to our professional service delivery and drawing on the expertise of our advocates. The training in best practice DAN disseminates is based on the sound practical experience of advocates gained in their day to day work for their clients.

In preparing this book, our aim was to explain the complexity and scope of dementia advocates’ activities. We did not want to produce a turgid manual, but rather a series of case studies to which the reader could relate. I hope that we have achieved this. But in any event, I challenge anyone not to be moved by these stories, which highlight the plight of our clients and the care and professionalism of the advocates who support them. It is unfortunate that the quality of advocacy demonstrated in the stories is available to a limited number of people with dementia in the UK. Until all statutory service providers recognise and fund dementia advocacy as evidenced in these stories, advocacy services to people with dementia will remain far too patchy.
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*The names of all the people in this publication have been changed to preserve their anonymity, except for Christine’s story which she agreed could be shared.
There is very little research into the impact of independent advocacy on the lives of people with dementia. This book is a collection of stories about the contribution made by advocates working in different organisations and different settings including care homes, hospitals and in the community, from across the UK. The stories are written from the perspective of the advocate, with some comments from people with dementia themselves. The aim is to demonstrate the difference that advocacy makes to the lives of people with dementia.

These are real stories and they show that advocacy is often a complex matter. Firstly the advocates are supporting people who are coping with a disease that affects memory, communication and mental capacity. This presents many challenges to the advocate who frequently has first to decide whether or not their client is competent in law to instruct them. A diagnosis of dementia does not necessarily mean an individual can no longer make decisions for themselves; an inability to communicate does not mean that an individual does not have mental capacity to make decisions. But whether the person has the capacity to instruct or not, the advocate’s job is to represent them and ensure their voice is heard.

Independent advocates support people to express their views and wishes, pursue their rights, make their own informed decisions, and to explore and understand the options available to them. To do this, an advocate needs to understand the impact of dementia on the individual and address the difficulties with skill and sensitivity. People with dementia often face discrimination and abuse, through ignorance and poor practice, from both family and professionals. Often those family members and professionals are not intrinsically bad but become impatient or frustrated in dealing with people with dementia as a result of lack of understanding or perhaps because of other pressures on them. Advocates need to be persistent and persuasive on behalf of the individual, reminding others of the personhood of the person with dementia. They are supported in this through legislation (The Mental Capacity Act 2005) and through the values set by National Dementia Strategies in England and Ireland and the National Dementia Vision for Wales.

The provision of all forms of independent advocacy to vulnerable people is insufficient. DAN supports the campaign to increase access to advocacy for all those who are vulnerable and in need of advocacy support, but especially people with dementia, who are among the most vulnerable of all. Some have friends and families to advocate for them, many do not. One of the advocates who contributed a story to this publication says “I often come away from such cases feeling that this person was lucky to have someone speaking on their behalf. How many people never get that help and support? ”

The stories contributed here by members of DAN are a sample of the many cases with which
advocates are involved. Whilst they do not cover all possible scenarios, the stories illustrate the frightening isolation of people wrongly assessed as lacking mental capacity (Andrew, Penny, Lionel), the barriers to accessing services (Bertram), the unfair treatment of someone with dementia (Frances), the difficulties of having your voice heard amidst opposition (Michael) or cultural barriers (Jameela and Dilip). The stories demonstrate how advocacy can transform people’s quality of life (Gerda, Christine, William, Hetty). People do not always get what they want (Norman) and some battles are ongoing (Dilip). Advocates often challenge people and procedures on behalf of people with dementia and their carers (Samira, Dilip).

As the title of this book states - advocates take the side of the person with dementia, very often fighting their corner. Advocates promote social inclusion, equality and social justice for people with dementia who are so often excluded. Some stories cover a short period of time, others go on for many months. Sometimes this is because of the time required to build a relationship with someone to gain their views, other times it is the multitude or complexity of the issues involved.

We intend these stories for a wide audience. We hope they will be useful to new advocates to learn from others’ practice, or for experienced advocates to reflect on their role. But we also aim to raise awareness of advocacy for members of the public or for professionals who come into contact with advocates. We hope too the stories will encourage funders and commissioners to recognize the value of advocacy in enabling personalization of services, the safeguarding of vulnerable adults and achieving positive outcomes for people with dementia by improving their well-being and quality of life – all key objectives in today’s agenda.

We hope you enjoy reading these stories and that they inspire you to support the campaign to increase the availability of advocacy for all vulnerable people. May they also encourage you to advocate for those you know who are living with dementia and whose voices may not otherwise be heard.

One more comment from an advocate...
“The satisfaction of walking away from a case knowing you have made a difference is priceless!”

Jan Kendall, DAN Manager
January 2012
Andrew
shedding tears of relief

The Independent Mental Capacity Advocate (IMCA) challenges the use of anti-psychotics and as a result dramatically changes Andrew’s world. The generic advocate supports Andrew to communicate his wishes and enables him to enjoy the last few years of his life. Working together the two advocates defend Andrew’s rights and safeguard him in a situation where other professionals had not respected his human right to be treated humanely, with dignity and respect, to make his own choices and experience a good quality of life.

Andrew was referred to the advocacy service by his GP for a statutory IMCA to assess his capacity to complete a resuscitation instruction form. He was 82 years old, a local man who after a period of time in hospital was now living in a nursing home. The advocate was informed that Andrew used a wheelchair, needed support to get in and out of his bed and chair and with meals and could not speak vocally.

When the IMCA advocate visited Andrew he was slumped in his wheelchair. The advocate needed to get down to his level so that she could see her face and she could gauge his response. Kneeling on the floor to gain eye contact the IMCA could see that Andrew’s eyes were dilated, suggesting that he was on medication. After explaining who she was and why she was there the advocate considered that he seemed able to understand what was being said. She tried getting him to squeeze her hand but that was too difficult; when it was suggested he blinked his eyes he did so rapidly. He was then asked to blink once for yes and twice for no. Within 10 minutes it was possible to ascertain that he had some mental capacity. He wept when the IMCA told him that she believed he understood what she was saying. That alone suggested he had capacity. It was not difficult to establish communication: sadly Andrew had at this point been in this home for 10 months with staff all assuming he lacked capacity and the ability to communicate.

Immediately, using the statutory powers of the IMCA, the advocate gained access to his medical records which noted Andrew had vascular dementia and also revealed he had been given anti-psychotic medication on the suggestion of the nursing home staff, to stop him being ‘difficult.’ Once communication was established, and secure in the knowledge that Andrew was able to make decisions for himself, it was easy to move forward. Looking beyond the IMCA role it was clear that generic advocacy was needed.

A telephone conversation followed with the GP to tell her that Andrew had the mental capacity to make decisions and one of those decisions would be about his medication. The advocate explained the

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1. It is estimated there are 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1,800 excess deaths per year as a result of their prescription.
2. The Mental Capacity Act 2005 states that every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise and that people must be given all appropriate help before anyone concludes that they cannot make their own decisions.
Advocacy changed the last years of Andrew’s life. Without it he would have remained over-medicated and in mental torment, with everyone around believing he lacked the capacity to communicate requirements of the Mental Capacity Act. The GP dealt with the medication issue promptly and also accepted the need for a referral to generic advocacy for ongoing support. The original question of resuscitation was speedily resolved: Andrew did not wish it and his notes were amended to show this decision and his capacity to make it.

Once off the medication Andrew was more alert mentally and a little better physically. He started to vocalise, although it was still difficult to understand him. He was happy to continue using eye blinking to communicate and even extended its use. Supported by a generic advocate, he was able to communicate his choices and was able to re-establish old interests, listening to classical music and enjoying his newspaper and books. The advocate’s visits were unannounced and this seemed to keep the home staff on their toes. It was reported that he was no longer difficult to care for and he was included more in decision making. He was supported with his ongoing rights as a resident in a care home by the generic advocate and through a befriending scheme.

Beyond the impact on Andrew’s life the intervention by the IMCA and generic advocate had a huge effect on the staff of the nursing home. The IMCA posed fundamental questions to the home about their communication skills: all staff have now undertaken training on challenging behaviour. The IMCA also questioned how dementia was being noted, asking for formal diagnosis. The generic advocate raised a number of more general care issues: she and the befriender maintained a watching brief. Care improved for Andrew, and hopefully for others, in the home.

Advocacy changed the last years of Andrew’s life. Without it he would have remained over-medicated and in mental torment, with everyone around believing he lacked the capacity to communicate. His tears of relief that someone finally listened to him speaks far more than words. There is an extreme contrast between Andrew slumped in his wheelchair, half awake but still desperately trying to communicate and the man whose face lit up, smiling with his eyes, when the advocate visited. Asked if he was enjoying life a little better now, Andrew blinked once.

The IMCA case was open for three weeks, with two visits; the Generic Advocate worked over six months with weekly visits; the befriender’s visits were weekly up to Andrew’s death.
Beyond the impact on Andrew’s life the intervention of the advocate had a huge effect on the staff of the nursing home.
The advocate gained his trust and respect by listening and accepting him as he was.
The advocate supports Bertram, who is homeless, in debt and struggling to manage his life, to get a diagnosis for his dementia and then guides him through the maze of agencies to bring some stability and hope to his chaotic life.

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Bertram, 71 years old, was referred to advocacy by a long standing friend who was very concerned for his welfare. He had been homeless for many years, living in his car or on people’s sofas and amassing a great deal of debt. At the time of referral Bertram was living in a hostel: his application for council housing had been refused on the grounds that he had made himself intentionally homeless. The friend who made the referral said that in her view, and that of others, something else was going on – perhaps a mental health issue, possibly dementia. Bertram was no longer coping, although his doctor had said there was nothing wrong.

When the advocate met with Bertram there were mixed messages. He presented himself well, seeming in control, but could then become aggressive, rude and racist in his comments. The advocate gained his trust and respect by listening and accepting him as he was. Bertram said his problems had started when he divorced and was left with his car and some money, but no home. He had worked with cars, drank and gambled but did not consider himself a heavy drinker. He had never claimed benefits, had no family contact and his only friends were drinking companions. Two falls had also caused him problems.

Bertram wasn’t managing and needed help to sort out his life. With his agreement the advocate first worked to overturn the decision on his housing application, arguing that having previously been quite responsible, Bertram had not made himself intentionally homeless: there were other factors involved. The GP was unsupportive: with the advocate’s support Bertram changed to another who was more understanding. The advocate requested a memory test to identify whether there was an underlying condition causing the problems: dementia was identified, possibly Korsakoff’s Dementia, caused by alcohol abuse.¹

Bertram needed legal advice to overturn his housing application but first he needed to sort out his finances. The advocate clarified his income but then discovered it was all being used to pay his substantial debts. He was also due benefits and backdated pension credit. Specialist advice was accessed to work out a plan to pay off his debt and still give him some money to live on. With Bertram’s finances in a better position the advocate was then able to access legal aid and contact a solicitor who helped overturn the housing decision.

Bertram was delighted: he now had money to live on and would no longer be homeless. The advocate had transformed his life by providing support at the doctors, the housing office, at the bank, at the solicitors. Sadly he died suddenly and never actually moved into his new accommodation.

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3. Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.
Christine  
the quality of her life addressed

The Advocate provided long-term support to Christine from the early days of diagnosis to her death, ensuring that her individuality was recognised and she continued to do the things she had always enjoyed when she finally moved into residential care. The advocate challenged poor care practice.

Christine was about 80 when she was first referred to the advocacy service by a friend concerned for her health and wanting to find someone who could ‘keep an eye on her’ during his absence abroad. She had had a very active life, working at Bletchley Park during World War 2, held an advanced driver’s licence, and was a champion bridge player winning many trophies. She worked as a maths tutor to 6th form students, and enjoyed travelling.

At that time Christine was still living alone at home since her husband’s death some years previously. The advocate was introduced and after some time accepted by Christine, as someone she could get in touch with if the need arose. Christine was at the beginnings of dementia but had not yet been diagnosed. She was increasingly forgetful, regularly mislaying her keys, not eating properly and generally becoming less able to manage her normal daily activities. She was very resistant to the suggestion that anything was wrong and fiercely independent. It was helpful that her close friend was able to liaise with the advocate: joint visits meant that Christine gradually came to be more trusting.

As Christine’s health deteriorated her advocate worked in co-ordination with a range of people and services on her behalf. Christine went through a difficult process of visits to her GP, capacity tests, formal diagnosis and the decision to withdraw her driving licence, which she found particularly upsetting. Additionally the GP immediately applied pressure for Christine to be admitted to Residential Care. Christine was distressed at this as she loved her home and especially her garden. Her advocate and friends felt strongly that she would still be able to function at home with appropriate support and this view was voiced with and for Christine.

A care plan was set up, involving Social Services, Home Meals delivery, the advocate and friends and with this support Christine was able to remain safely and happily in her home for a further year before she needed full time care. However a move from the first Residential Home became necessary due to poor standards of care, recorded and highlighted by her advocate and friends. Care was better in the second home but there was still a need for continuous monitoring, to deal with issues such as being offered food she did not like; not always being dressed in her own clothes; jewellery and glasses going missing; being restrained in a wheelchair; erratic standards of cleaning.

4. People with dementia moving into care homes face enormous challenges. In addition to declines in cognitive powers such as remembering, reasoning and being aware, and arguably an increased need for familiarity and human contact, people have to cope with a new and often unpredictable care environment. They may also be cared for by people who often know very little about them and who, in some instances, focus on their safety rather than their emotional well-being. See me, not just the dementia Understanding people’s experiences of living in a care home, June 2008
The advocacy service made the commitment to support Christine long term. She was in effect alone and a self-funder and had developed a close trusting bond with her advocate, who now knew her well and felt able to truly represent her as Christine became less able to communicate her wishes, feelings and choices for herself. The advocate visited Christine regularly, monitoring her care, addressing problems as they arose, attending Care Plan review meetings, keeping in contact with the solicitor who looked after Christine’s money and monitoring her financial affairs. The advocate also arranged for Christine to do some of the things she had always enjoyed, such as going out for lunch and going on shopping trips. She kept in touch with Christine’s friends to let them know how she was getting on and kept watch, making sure that people could not do anything she wouldn’t want.

The changes that were made to Christine’s care as a result of the intervention of the advocate included appointing a Key Worker: after much resistance from the Home and with the agreement of her solicitor, additional staffing was allocated to Christine, for which she could afford to pay, to give her more support and personal contact in the Home. Christine paid for and was given the particular foods she liked: staff assisted her at meal times to ensure she was able to enjoy it. Christine was able to make trips out for tea, to shops and garden centres and had her favourite music playing in her room.

The advocacy service supported Christine for over ten years, up to the time of her death, aged 90. In this story we have kept Christine’s real name. Christine was a very strong willed and highly intelligent person and she had no concerns about people knowing her story especially since her advocacy service was using it to help other people and with training. She was asked about this many years ago when she was well enough to understand and answer for herself. In her later years her closest friends confirmed repeatedly that this was something to which she would wholeheartedly agree.
Dilip
he still has the will to fight

The advocate stands alongside Dilip, supporting him in his fight to go home, ensuring he knows his rights and his views are heard. Dilip faces opposition and rejection from his family and a constant battle with alcohol.

Dilip is 79 years old and from a Sikh Punjabi background. He is a proud family man who has worked hard all his life. He is strong-minded, a patriarchal figure with very fixed ideas who has supported all his children to get degrees. He is proud too of the home he built for his family. His dementia was diagnosed as being brought about by excessive alcohol consumption. Over a period of 4 years neither Dilip nor his family had understood why he was behaving so oddly but attributed all his aggression and mood changes to him becoming older and less tolerant. He would wake in the night and make loud noises, would not use the bathroom and had been abusive to his family. An incident with one family member led to others urging that the police be called in. This led to Dilip being detained in hospital under a Section 3 order of the Mental Health Act, initially for 6 months.

Dilip was extremely unhappy in hospital and could not understand why he was not being allowed out. It was at this point that the hospital staff made a referral for advocacy to help him appeal his detention. The Punjabi speaking advocate met with Dilip in the hospital. While he spoke good English and better Punjabi, Dilip was insistent that they spoke in English, even though this meant that the advocate was at times unsure that he understood everything being said. Gaining Dilip’s trust was not easy; he seemed to need to retain control and dignity in a situation where his authority was being questioned.

Dilip made clear to the advocate that he wanted to leave the hospital, and so her first action was to instruct a solicitor to appeal his detention. Dilip appeared to have no insight as to why he was being detained so she explained the reasons, repeating this several times as he would forget. His view was that he needed to be at home, there was no reason why he should be kept in hospital. Whilst he was polite with the advocate he was increasingly angry with his family. By the time the appeal was lodged the doctors felt Dilip no longer needed to be detained as he was not a danger to himself or others anymore and was accepting of the treatment offered. Under the law he was now free to leave, but the doctors wished him to remain in a hospital setting voluntarily for further treatment.

He was moved to a different mental health facility where he stayed for a further 3 months. Dilip continued to ask the advocate to tell people that he wanted to go home which she did at the Care Plan Meetings. The advocate persisted in stating to other professionals that Dilip was no longer drinking, that there was no reason why he needed to be in
hospital: with a package of care he could manage at home. His family was opposed to this because of his previous behaviour but the advocate informed them that he had a right to go home. The advocate also requested an assessment of Dilip’s needs and a month later Dilip went home.

Initially Dilip was happy to be home but life was not the same and one month later his wife moved out. Dilip gradually began to drink again, then he had a fall. A case meeting was held with social workers expressing their concern over his safety. The advocate continued to support Dilip, representing his view that if the risk of falls could be managed he should remain at home. There was also a complaint that he was refusing to be bathed - the advocate probed, discovering that the care worker concerned was female and this was unacceptable to Dilip because of his cultural beliefs: this was resolved.

Dilip remained at home but continued to drink and was not eating: this increased his confusion. The advocate’s relationship with Dilip was growing slowly, he recognised that she was on his side. At the discharge meeting planning his future care it was proposed that Dilip should go into a care home: he flatly refused, saying yet again he wanted to go home. On his behalf the advocate pressed the doctors and social worker to reconsider the options and make a more informed decision about his care needs. It was agreed that while Dilip lacked the capacity to make a decision about where he lived, he could manage at home with support. The family continued to resist. The advocate pressed his case, arguing there was no reason other than family pressure for Dilip to be in a care home. After further meetings it was agreed that he could go home, with a contingency plan in case things went wrong. These plans were sabotaged by family members who would “forget” the house keys and finally, the day before Dilip was due to leave, his wife gained a court injunction to prevent him from going home.

Dilip was distraught. He would say “What have I done wrong, that I’ve ended up in a little room like this?” The advocate worked to support him in appealing the injunction, instructing a solicitor who found that Dilip lacked the capacity to instruct and did not accept the issues that had led to him being sectioned: the solicitor felt an appeal would lose. Dilip was then moved to a care home. The advocate visited, finding him unhappy but accepting of the situation. His health gradually improved and after 3 months he was asked if he wanted to move to a sheltered flat. The advocate spent time explaining to Dilip what this might be like, to be sure he understood and was in agreement. It was finally
established that Dilip believed that if he moved, he would be further isolated and forgotten, whereas if he stayed at the home, he would have better grounds in his fight to get back home.

Some months later, Dilip was told that he no longer had a diagnosis of alcohol related dementia, and did not need to remain in the home. He could move elsewhere. However he was determined to stay: the advocate helped him voice his views to the management of the care home.

In the care home Dilip felt isolated and kept to his own room for most of the time; his cultural needs were not addressed in a home where he was the only Asian resident and he didn’t want to make a fuss. The advocate supported Dilip to enable appropriate meals to be offered, visits to the temple arranged, his turbans and other possessions to be brought from his home.

Dilip again asked the advocate to instruct a solicitor to get him back home. Legal aid was granted, then withdrawn and finally reinstated with the advocate arguing that he was being discriminated against on grounds of age. The advocate constructed his case for returning home and obtained a referral to a new social worker who has suggested the house be split, to accommodate both Dilip and his wife. Dilip’s wife initially agreed but now the family are adamant they do not want Dilip home. The case will now go to a hearing where the advocate will continue to support him. The advocate says “I have informed Dilip that the outcome may not be in his favour, but I realise that Dilip chooses not to hear this part of the conversation.”

Getting to know and understand Dilip was a real challenge for the advocate - to understand the huge embarrassment Dilip felt at not living in his own home and how he felt he would be looked down on by his community and understanding his anger at his family for rejecting him when he had no knowledge of his behaviour. As the trust grew Dilip began to speak in Punjabi with the advocate – this enabled Dilip to express his feelings in more depth. He felt intimidated with solicitors and did not engage well; he was unhappy but compliant in the care home because his culture taught him to accept authority.

Dilip’s fluctuating dependency on alcohol and its impact has made this situation a difficult journey for the advocate. Sticking with Dilip through all the changes has been problematic, but if the advocate had not persevered Dilip’s wishes would have been over-turned, his voice not heard against others with stronger voices and views. When not influenced by alcohol Dilip is obviously a more capable person and his dementia symptoms diminish. Through it all Dilip himself still has the will to fight for what he wants.

The advocate has visited Dilip 90 times over a period of two years with many phone calls on his behalf and is waiting to support him for the next stage on his quest.
Frances was referred for advocacy by the Community Psychiatric Service. She was 71 years old and in the early stages of Alzheimer’s disease, with occasional periods of short-term memory loss. Frances lived in the same street as her 94 year old mother Betty who has age-related memory loss. Betty has daily visits from a care team to assist both her and her 68 years old learning disabled son who had been cared for by his mother since birth. For many years Frances had been visiting daily to help care for them both.

Social Services were proposing that Frances should be moved from her home so that she would not be able to visit her mother and brother so often. The carers felt that Frances was becoming a nuisance and interfering in her mother’s care. It was also reported that Frances was visiting her mother at night, sometimes sleeping over, and this was causing Betty to become over-tired. A meeting had been arranged to formalise a decision about a move for Frances.

When the advocate first visited Frances it was evident her communication skills were good. She was able to articulate clearly, make her views and opinions known and to retain and recall information from varying time-spans. Frances said that she had lived across the road from her mother for many years, always helping her mother care for her disabled brother. Now that her mother was herself in need of care, Frances wanted to help with this too. She said that they were a “very close-knit family” but that since carers had been providing a service to her mother, she had been “pushed out”. She was been told by her mother’s Social Worker not to visit her mother’s house when carers were present or after 8 o’clock at night. Frances also said that she had looked after her mother’s finances up until recently but had “got into a muddle” and another family member had now taken over this role.

All she wanted was her family near her and for them to visit her every day

The advocate asked Frances how she felt about the suggested move. Frances’ replied “if they moved me 50 miles away, I would still visit my mother and brother everyday.” Asked if she would like the advocate to attend future meetings Frances said that she would like the advocate there because “meetings frighten me and I don’t like what they are trying to do.”

Frances and Betty seen as an interfering nuisance

A close-knit family is under threat of being broken up until the advocate takes time to listen to their views and then takes up their cause, recognising their rights under the Human Rights Act.  

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6. The Human Rights Act states that ‘You have the right to respect for your family life’ ‘to enjoy your family relationships without interference from the government. This includes the right to live with your family and, where this is not possible, the right to regular contact.’

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It emerged that a number of allegations had been made about Frances: a family member had reported to Social Services that over £50,000 had gone missing from Betty’s account and that Frances had taken it and given it to her children. On investigation this was not proven. An allegation was then made that Frances was sleeping in the same bed as her brother. Frances’s Social Worker was informed that her advocate would be attending future meetings: when the advocate asked where it was expected Frances would go in the proposed move the reply was that this was not yet known. The planned meeting to discuss a move for Frances was then cancelled. Because Betty’s views on these subjects were unknown, the advocate arranged separate advocacy for her. Betty’s advocate established that she too retained good communication skills and articulated her wishes clearly. Although Betty was not told of the intention to move Frances away, because of concern at the detrimental effect this could have, Betty was told of the complaints that Frances’s visits to Betty were interfering and causing her to be over-tired. This gave Betty the opportunity to voice her views: she said that the family were “very close” and had lived nearby all of their lives. All she wanted was her family near her and for them to visit her every day. “Frances has been helping me with her brother since she was a girl, for which I’ve always been grateful, and I wouldn’t want her to stop now.” Betty also confirmed that Frances did not sleep in her brother’s bed but often stayed the night as she wanted her mother and brother to feel safe.

Frances’s advocate discussed the matter with her Social Worker, explaining that there was potential for a strong family relationship to be destroyed if Frances were to move. Both Betty and Frances had a right to maintain their contact and had expressed the wish to do so: the fact that both had dementia should be taken into account and their relationship maintained for as long as their dementia allowed.

Some days later the advocate was informed that Social Services would not be pursuing their action against Frances. Advocacy proved essential in this instance because at her most vulnerable, Frances could have been pressurised into moving from her home and away from her family which could have had catastrophic consequences for both mother and daughter.

This case took three months and involved six visits to Frances and one to Betty.
Gerda
a purpose in life once more

The advocate enabled Gerda to plan for her future financial needs and to record her end of life wishes. Through their conversations the advocate was able to build a picture of Gerda’s life – lonely, frightened, hopeless, without purpose - and together they worked out a plan to change things for the better.

Gerda is an 88 year old lady from Switzerland who has lived in the UK for over 30 years. She lives alone, has vascular dementia and Parkinson’s Disease. She was referred for advocacy by social services because of worries about her ability to manage her finances.

The advocate’s first task was to identify the options for Gerda, checking whether she wished to set up a Lasting Power of Attorney or Appointeeship to manage her finances and see if she had anyone in mind to take on that role if she lost capacity to make those decisions. Meeting with Gerda in her home, the advocate explained why she was there and discussed the options. Gerda opened up to the advocate telling her that she had separated from her husband many years ago and was sad that she had no contact with her son who had chosen to live with his father. She had just one close friend.

After some discussion Gerda decided she wanted her grand-daughter to manage her finances and set up a Lasting Power of Attorney. She also agreed an advance decision on what was to happen to her ashes when she died.

As the financial issues were being decided it became clear that Gerda was quite isolated. Gerda’s face lit up when she spoke about her cat who had died two years before and said that she missed having a companion, someone to look after and care for. She knew she had problems with her memory and people had told her she cannot have another cat – how can she look after a cat if she can’t even look after herself properly?

With Gerda’s consent the advocate discussed the situation with social services. It was agreed that a cat could form part of her care plan. Despite opposition from a neighbour Gerda now has a cat brought by one of her carers. She feels the cat knows her, understands and communicates with her and she is able to look after him herself: she has a purpose in life again. She has become more outgoing, had her hair cut and takes more pride in her appearance.

The cat has made a real difference to Gerda’s life but beyond this she says that having someone who listened to her and treated her with respect and dignity made her feel much better. Talking with the advocate she was able to confide aspects of her dementia and her feelings about her life she had not previously shared with anyone.

7. One of the key outcomes of the National Dementia Strategy states that ‘people living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active a life as possible... to be happy and feel fulfilled while living with dementia’

The advocate made 14 visits over a period of six months.
The advocate supported Hetty to get a diagnosis and anti-dementia medication, accept regular support, improve her finances, her health and well-being so that she is now able to stay in her own home.

Hetty, 85 years old, lives alone in the neighbourhood where she has lived all her life. She never married, has no living family or close friends and was referred for advocacy by a friend who lives some distance away and visits every few weeks. Hetty has Alzheimer’s disease.

Visiting Hetty in her own home, the advocate discovered her in a very vulnerable state: she had not seen her GP for many years, her short-term memory was extremely limited and made worse by her malnourishment and vitamin deficiency. Social Services had set up a care package, but Hetty’s confusion and lack of understanding meant that she refused to let the carers into her home.

The advocate used her communication skills alongside constant repetition and reinforcement of new ideas to reassure Hetty. Extra time was allowed to get her to appointments, moving at her own pace. The advocate always left a note in Hetty’s diary reminding her when to expect the next visit.

Initially the dementia advocate organised an appointment with the GP for a full physical health check and accompanied Hetty to ensure she got there. As a result of the check-up Hetty got the anti-dementia medication she needed. The advocate liaised with the care agency to ensure that shopping was done on a regular basis: before this Hetty was regularly without food in the house but now the fridge is well stocked and she has started to regain some weight. A full Benefits check was carried out and successful application made for the Care Attendance Allowance and for Council Tax exemption. Hetty is now over £3,000 a year better off.

Hetty was seen as a priority case for advocacy with twice weekly visits initially, later reducing to weekly. Because of her fear of strangers it was first necessary to establish a relationship of trust. Short-term memory loss meant she would ask the same question every five minutes: this worsened when she was anxious, rushed or in an unfamiliar environment.

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8. 51% of all people over 75 live alone. ONS General Lifestyle Survey 2010. Nearly two-thirds of people with dementia live in the community.
Five months on, Hetty’s situation has improved dramatically: now that she is on the right medication her medical conditions have stabilised; she is accepting a care package of two visits a day and, most importantly, she benefits from the stimulation provided by the advocate during weekly visits.

When the dementia advocacy service first became involved with Hetty the professionals involved were considering a move to residential care to be in her best interests. Following the intervention, however, the advocate called another ‘best interests’ meeting at which it was decided that Hetty had improved so much that she was now safe to remain at home.

The family friend, who initially referred Hetty wrote in an email to the advocate: I must say that I'm amazed at how the interaction (and regular food!) has been so beneficial to her. I didn't expect to see such an improvement. And Hetty said to the advocate : “I’m not sure who you are exactly but I feel like you’re a Guardian Angel dropped from heaven.”

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Sara is a professional working in the Asian community. She first met Jameela 14 years ago at a family wedding. Jameela was aged 40, smart, very pretty, confident, running a business with her husband. Sara saw her a few times over the years but in her early fifties noticed changes: Jameela would forget the names of her children, would drive somewhere then walk back, forgetting her car. One day she was holding a baby and said it was 9 years old. Jameela would laugh about her mistakes but Sara thought something was wrong: this was not normal forgetfulness. She spoke of it to the family but they knew nothing about dementia so ignored what Sara said. They were busy with their business. Jameela got worse, one day she fell and was taken to the GP who diagnosed high blood pressure. Appointments were made to check this regularly but Jameela didn’t keep them. Sara saw Jameela changing so fast. She had had training in dementia through her work and knew the signs. Sara tried to speak up for Jameela but it was difficult to know how far to go without upsetting family relationships. She said to Jameela’s son-in-law “I think something is wrong with your mum. Don’t you think she should see a doctor?”

Neither Jameela’s husband nor the GP thought there was anything seriously wrong but eventually it was agreed that Sara would accompany Jameela to a private consultation. There she had a lumbar puncture and a series of tests. After six weeks they had not had any results so Sara went with the family to the GP who told them that Jameela had vascular dementia. Jameela’s son-in-law argued with the doctor for not telling them sooner and Jameela’s husband kept silent. It was left to Sara to ask questions. The doctor said “It is very advanced, there is no cure. There is medication recommended but it is very expensive.” The GP said he would
Jameela is 57 now. Sara phones the family and asks how Jameela is and they say she is fine. This makes Sara angry. She tries to speak up for Jameela and get her the help she needs but the family is ashamed that people might think Jameela is mad. Sara invited Jameela to a big family wedding, the family kept making excuses but eventually they took her. When Jameela arrived her foot was in plaster and her leg was swollen from ankle to knee. Sara confronted the family saying they must take her to casualty for an xray. At the hospital the nurse said “It could have caused an infection - you may have saved her life.”

Sara spoke to the family about finding things for Jameela to do. She arranged a meeting for the family with the local Dementia Care Service. Eventually they agreed that Jameela could go to a daycentre where many other Asian people went - she went 3-4 times but then stopped. Sara invited the family to make an appointment with her consultant and said she would go with Jameela as they were all busy. The family got her ready for the appointment - she looked so young and pretty the doctor couldn’t believe she was the patient. Sara explained that she was a relative of Jameela’s but also a professional who understood dementia. He checked the file and was angry that the appointments to check on her blood pressure had not been kept in a whole year.

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Sara asked how he could support Jameela to be more active. He immediately arranged a place in a specialist centre with transport provided, where her condition would be monitored. This centre was mostly white English speaking people. Her husband went with her twice, Jameela really liked it but then they stopped going. She is back at home now with a carer helping her bathe, have breakfast and to take her for a walk. She is still not having her blood pressure checked.

Jameela is becoming more difficult to care for now, she gets angry and blames others for things that go wrong. Her husband is very depressed: “We can’t go on holidays anymore, she needs help to go to the toilet, I can’t leave her at home, I can’t ask people to look after her, I am only 60 but my life is ruined.”

For the family the stigma of dementia is overwhelming. Sara has found a good care home for people with dementia that would give Jameela a better life but the family are too ashamed to do this. Sara has suggested they employ a trained dementia nurse to care for her in her own home, providing personal care and taking her out. Sara is frustrated; she hopes that one day they will listen and understand.

As a family member Sara has acted as an informal advocate: she has tried to speak up for Jameela in the family setting and at meetings with service providers, to help get the services Jameela needs and improve her quality of life. Sara has been hampered in this because of the family’s lack of understanding of dementia and the stigma and fear it presents them. This story illustrates the tensions experienced by a family member acting as an informal advocate, who lacks the formal status of an independent advocate and has her own personal issues about maintaining family relationships. It also illustrates the difficulties of engaging with people from diverse cultures and the barriers they face in addressing dementia.

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**Kim**

**taking his side**

The advocate supports Kim to manage his own finances and care plan, obtain legal advice, set up the person of his choice for Lasting Power of Attorney, manage family conflict and prevent further financial abuse by a family member.

Kim is a 76 year old man with Diabetes, who lives alone with care support from social services. He was referred for advocacy by his social worker after he had been discharged from a Mental Health Section to his own home. The referral asked for support with financial issues and identified conflict in the family. The social worker requested a male advocate as Kim was a strong man with aggressive tendencies and an intimidating manner especially towards women.

The advocacy service conducted a risk assessment and on investigation discovered Kim had a female CPN and a female social worker who both undertook lone visits to Kim’s home. It seemed that incidents of aggression were specific to particular situations and along with the advocacy service manager it was agreed it was appropriate for a female advocate to take on Kim’s case.

The advocate was informed that Kim had been admitted to hospital following being “found wandering”. His insulin levels were low, he’d not been eating, was confused and disorientated. Violent behaviour both in hospital and at home was alleged and the social worker said she had witnessed family conflict. Kim was moved to a psychiatric hospital ward, placed under Section 2 of the Mental Health Act and subsequently he was diagnosed with Alzheimer’s disease.

On her first visit to Kim the advocate found him to have mildly impaired cognitive functioning, typical of the early stages of dementia. In general he was articulate and lucid. When discussing his finances it was clear he didn’t know how to pay bills or budget his money, but this was not due to his dementia: his wife had always looked after their joint finances. They had been married for 56 years but his wife had left him 4-6 months ago saying she didn’t want to care for him now he had dementia. Kim said that she had taken most of their money and would not allow him access to the joint bank account or bank statements. Kim had tried to manage things himself – he could write letters but often lost them or couldn’t remember whether he had posted them, did not keep copies and couldn’t remember what he had written.

The advocate established that Kim was able to instruct but needed help to understand his rights and entitlements, to organise his thoughts, and to be given sufficient time to make decisions. He needed reminding of decisions he had made or courses of action chosen. He felt family members would try to tell him what he should do but rushed him and ended up making the decisions for him and discounting his wishes. He sometimes felt bullied by them. One technique the advocate used to help is that when Kim made a decision, he wrote it down followed by the
phrase “I made this decision after careful thought”, and signed and dated it. When he forgets, he is shown the paper, and he is reassured, often then remembering making the original decision.

For the care planning meetings arranged for Kim the advocate provided structured support by helping him prepare for meetings - explaining what they were about and the procedure in a way he could understand, supporting him during the meeting then following up afterwards.

The advocate supported Kim through a number of issues, including getting a bank account in his own name, discussing the setting up of a Lasting Power of Attorney for his daughter to manage his finances with a solicitor and negotiating with the DVLA over the withdrawal of Kim’s driving licence due to his dementia.

A critical need for advocacy emerged with the involvement of the Pension Service. Kim was visited by a representative from the Service about his claim for pension credit who decided he lacked the capacity to manage his own claim. At Kim’s request the advocate contacted the Pension Service and explained her role. The Pensions Officer said he had already spoken to Kim’s wife and daughter and they had decided between themselves that Kim’s wife should be appointed as Kim’s Appointee, acting officially for him in relation to his pension. Kim was opposed to this and asked for his daughter to be appointed. This was fed back to the Pension Officer who said that Kim’s daughter didn’t want to be the Appointee, and saying that he had the authority to appoint someone against Kim’s wishes. A meeting was held in Kim’s home inviting Kim’s wife and daughter. Kim phoned the advocate when they arrived, but when she arrived 30 minutes later Kim had signed papers appointing his wife. He said he had felt under pressure and had no choice but to sign the papers put before him.

The advocate and Kim went to his bank: bank statements provided evidence that his wife had been making withdrawals from Kim’s account without his knowledge or consent. She had set up monthly direct debits to pay for her mobile phone and mobile internet. Kim cancelled these.

The advocate checked Department for Work and Pensions policies on Appointees and found that the DWP cannot appoint someone who is unsuitable. Kim authorised the advocate to write to the DWP on his behalf, asking for his daughter to act as Appointee. The advocate enclosed evidence of withdrawals by Kim’s wife, explained the situation,

The advocate established that Kim was able to instruct but needed help to understand his rights and entitlements, to organise his thoughts, and to be given sufficient time to make decisions.
quoted relevant sections of the policies, and requested that the Appointeeship be cancelled. The DWP did so and this then became subsumed into the Power of Attorney now held by Kim’s daughter.

The issues are not wholly resolved. Kim’s daughter still seems unclear of her responsibilities under the Power of Attorney – she says she understands them but in practice is not involving Kim in decisions, nor acting on his requests. The advocate has helped Kim access free legal advice, kept notes of the advice and fed back to the daughter. On instruction the advocate wrote to his daughter and to his wife’s solicitors recording Kim’s wishes and asking for copies of correspondence. The outcome is still awaited.

Advocacy has been important to get Kim the right legal advice in a way that works for him rather than other members of the family. He was very relieved to have someone independent to take his side, and to feel in control of his own choices. Advocacy made him more confident and the advocate took time to explain issues in such a way that he could understand and then make decisions for himself.

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This case is still open. Over 18 months there have been 13 Home visits, 13 Phone calls with Kim, 24 Phone calls about Kim and 24 letters written on Kim’s behalf as well as attendance at many meetings.
Lionel was in his 80s and lived alone. His only relative was a sister who lives abroad. Lionel relied heavily on his friendship with his neighbours on either side of his home. He had professional carers coming in to help meet his physical needs each day but had developed severe pressure sores, made worse by Lionel becoming increasingly self neglectful. He spent most of his time sitting in his chair, not going out and not going to bed at night.

Some weeks before Lionel was admitted to hospital, the relationship with his carers broke down and he began refusing them access. His physical condition was deteriorating and his home had become very dirty and unhygienic. Lionel’s doctor felt he was becoming confused and possibly developing a form of dementia. At this point Lionel was put on a Section 2 order under the Mental Health Act, and brought to an older person’s psychiatric ward at the local hospital for assessment and treatment.

Lionel was referred to the advocacy service for an IMHA by the Ward Manager. At the first visit the advocate carried out an assessment and established that Lionel was able to sign the necessary forms to say that he understood the advocate’s role, understood the confidentiality policy and consented to work with the advocate. The advocate explained Lionel’s rights to appeal his detainment in hospital and the procedure to take.

Two days later the advocate attended Lionel’s Mental Health Review Tribunal at his request and his solicitor was also there to represent him. The advocate supported Lionel in putting forward his view that he did not think he should be in hospital and wanted to return home with care support. The Responsible Clinician, the Community Psychiatric Nurse and the Ward Manager all took the view that Lionel would not be able to return home and needed to be placed in a 24 hour care facility. The Section was left in place.

Communication was not easy. Lionel had a pronounced stammer, often struggling to get his words out. He did not recall the advocate’s role from visit to visit... though he always remembered the advocate’s face and name.

The Independent Mental Health Advocate (IMHA) supported Lionel to appeal his detention in hospital, explained the process and his rights. A request for a mental capacity assessment results in Lionel making his own decision to return home and reversing the opinion and approach of professionals.

He did not recall the advocate’s role from visit to visit... though he always remembered the advocate’s face and name.
Back on the ward Lionel’s advocate helped him to understand the decision regarding his future and his subsequent rights. The advocate explained that the Section still had 14 days left to run and he would be in hospital for at least that period of time. Although Lionel was keen to go home he accepted the decision. The advocate attended Lionel’s ward reviews with him, having spent time talking to him and helping him to decide what he wanted to happen about his current and future care and treatment. With Lionel’s consent, the advocate then fed back to the care team.

The Care Co-ordinator raised the issue of mental capacity with the advocate and it was explained that under the Mental Capacity Act if there were concerns then a capacity test must be carried out to establish whether Lionel had the capacity to decide where he wanted to live once discharged from hospital. The assessment was carried out and the test showed that Lionel had the capacity to make this decision.

This marked a change in the approach of the care team who now began to plan appropriate care for Lionel to receive on returning home. Lionel was pleased at this and at that stage was enjoying the social life on the ward, so was in no hurry to go home. The crucial thing for Lionel was that he was going home eventually and he understood the team needed time to put an appropriate care package in place. Lionel now was taken off his Section, remaining as an informal patient. He was diagnosed as having mild dementia.

The advocate asked Lionel whether he would like to continue having the services of an advocate when he returned home, explaining that it would no longer be from the IMHA service but a generic advocate from the same organisation. Lionel said he would like to be referred and the IMHA continued to work with Lionel until a handover to a new advocate was achieved.

Once the question of Lionel’s capacity was clarified, his care team began to involve him more in decisions and followed his wish to return home. Working with his advocate, Lionel became less anxious about what was happening to him and his involvement in decisions being made. He felt he had been listened to by the care team and was pleased he was going home.

This case lasted for two months and involved 10 visits.
Margaret
advocacy came too late

Misunderstandings, conflicting views and opinions on her capabilities meant that Margaret was living in a care home when she could have been living in her own home as she wanted. The IMCA pursued Margaret’s rights and wishes but the referral sadly had come too late.

Margaret is 86 years old and has lived on her own for many years in a cottage near a remote village in the country.

Margaret’s GP and her community support worker referred her for an IMCA, an Independent Mental Capacity Advocate. Some 3 months earlier a concerned neighbour had called Margaret’s GP, who had then admitted her to hospital in a state of “acute confusion”. She had been diagnosed as having vascular dementia. After a few days in hospital she had been discharged to a residential care home for a two week stay and was still there. The referral form stated that there was a unanimous view that it was not safe for Margaret to return home: discharge home with a care package had already been tried and failed. After only a couple of days at home Margaret was found wandering in the rain near her home by a neighbour and returned to the care home.

The advocate met with Margaret at the care home and at the same time met the care home manager, looked at the care home records, and met with Margaret’s solicitor who had known Margaret for many years and held Power of Attorney for her. The IMCA met with Margaret just once but she was both clear and articulate about what she wanted: she wanted to go home. She hated the care home and what she experienced as the staff’s patronising and intrusive attitude. She liked to do things for herself, in her own way. Margaret pointed to the post office directly opposite her window, on the other side of the street: she wanted to pop out to the post office when she wanted, but this wasn’t allowed. She was angry about this, and about the way staff assumed she couldn’t do anything for herself.

The advocate saw that Margaret was struggling to understand how she had arrived at the home: they talked through what she remembered of the fateful weekend when her return home had apparently “failed”. The key things Margaret remembered was that her phone was not working and that a supportive neighbour had gone away on holiday – two circumstances that had left her feeling isolated and frightened. She remembered that she had gone out to try to find another neighbour to talk to. “Wandering” is a term that can be used in a rather disparaging way (as in “she was wandering, poor dear, with no idea where she was”); but Margaret’s search for help on that rainy day had clearly been purposeful.

It was clear that Margaret wished to go home. The advocate needed to understand the risks involved in
her being at home and what should be put in place for her to manage. Why had the trial weekend failed? The advocate looked at all the documentation, spoke with staff from the hospital, her GP and an occupational therapist who had undertaken a home visit with Margaret. From all this, a picture emerged. Margaret had been sent home on a bank holiday weekend; a care package had been organised, with care workers visiting twice daily which had worked very well: Margaret said the carers were “delightful”. However the phone had been cut off because Margaret had forgotten to pay the bill, there had been a big thunderstorm and her nearest neighbour had gone away. Another neighbour, no doubt well meaning, seemed to over-react to her anxiety and called for an ambulance. The same neighbour said that Margaret’s home was “uninhabitable” and that she should never be allowed back there. However this was not backed up by anyone else.

The GP said that Margaret got terribly anxious and distressed, needing lots of reassurance, especially in the evenings, going so far as to say that it would be “cruel” to allow Margaret to go home, as she couldn’t possibly manage. The care home agreed: she needed 24-hour care. They reported that Margaret was very confused in the early afternoons, but on probing the advocate found that she appeared confused because she wanted to go to the shops and could not understand why she needed a member of staff to go with her. Confused or outraged the advocate wondered. Despite the care home’s assertion that Margaret could do nothing for herself their records showed that in fact they were only providing meals, since Margaret was refusing assistance with personal care, even doing her own laundry. The home’s written assessment stated clearly that Margaret was independent in all personal care, able to assess risks for herself, and not at risk of falls.

The advocate proposed that arrangements be made to get Margaret home as soon as possible, initially with a more intensive care package.

The advocate realised that if it were to be possible for Margaret to return home quick action was essential. Key risks were listed and tentative suggestions made as to how these might be addressed. Suggestions came from those consulted: for instance the solicitor said she intended to visit weekly, to pick up financial paperwork and ensure bills were paid. The advocate proposed that arrangements be made to get Margaret home as soon as possible, initially with a more intensive care package. Since she had now been away from her home for some 11 weeks, the first days at home were likely to be critical. It was also suggested that the community care worker speak with the over-concerned neighbour, whose intervention seemed likely to cause the venture to fail. Perhaps if Margaret appeared confused, the neighbour might accompany her home and sit with her over a cup of tea, instead of calling an ambulance?

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11. Risk enablement goes beyond the physical components of risk, such as the risk of falling over or of getting lost, to consider the psychosocial aspects of risk, such as the effects on wellbeing or on self-identity if a person is unable to do something that is important to them, such as making a cup of tea. ‘Nothing Ventured, Nothing Gained’: Risk Guidance for people with dementia July 2010
Sadly this story does not have a happy ending. The Community Care Worker, who was the lead decision maker in the IMCA process, organised a care plan for Margaret’s return home, though this took some time. But on hearing this, the care home, convinced that Margaret couldn’t manage at home alone, issued a Safeguarding alert, a referral to the local Safeguarding Team. Again this took time to investigate. The advocate had no part in this procedure but was told subsequently that the local safeguarding team concluded that Margaret should have the chance to go home with a package of care. Just two days before this was due to happen however Margaret’s condition deteriorated. She took to her bed, appeared much more muddled and confused than previously, talked about meeting her parents when she got home. Visits from the Community Care Worker, Community Psychiatric Nurse and the solicitor who knew her well all concluded it was not now in her best interests to move. The Community Care Worker said that in this case “time was of the essence and I think we have missed the slot”.

The advocate says: “This is one of the saddest situations I have worked with as an IMCA. I am still sad that Margaret was deprived of her last weeks or months at home and feel she was deprived of her rights. The IMCA referral was made far too late.”

“time was of the essence and I think we missed the slot”
stories of dementia
Michael
fighting his corner

The advocate supported Michael in his wish to live in his home, ‘fighting his corner’ against his family’s opposition and looking for strategies to support the family and make it work.

In his early 80’s, Michael, who had a diagnosis of Alzheimer’s disease, was referred for advocacy by his Consultant Psychiatrist. He had been an active and independent man, living at home with his wife. He had three daughters and several grand children. At the time of referral, he was an in-patient in an old age psychiatry ward in a local hospital, admitted for emergency respite as his family found his erratic behaviour difficult and there had been an incident when his wife felt threatened.

Since his hospital admission he had been very settled, and there were no signs of challenging behaviour to cause concern. Michael wanted to return home but his family wanted him to go into full time care. The Consultant determined that Michael had the capacity to make his own decisions regarding his future care and wanted to ensure that he had someone independent to advocate on his behalf in this difficult situation.

The advocate met with Michael on the ward and found him to be a pleasant, well presented gentleman who was happy to engage in conversation. He spoke of his past working life, of his family history and childhood, and fondly about his family and grandchildren. When asked what he would like to do on discharge he clearly stated his wish to return home. He acknowledged that he had “problems with his memory”, and that while he was largely independent with his care needs, he would be willing to accept help in the form of a care package involving meal provision. Other alternatives such as supported living or residential care were discussed, but he was always clear and consistent in his wish to return home.

The advocate met with Michael on several occasions, each time outlining the role of an independent advocate and agreeing a plan of action with him. In these sessions, despite having memory difficulties, Michael communicated very clearly, and was always able to instruct in relation to his wishes. He recognised the advocate when she visited, and while he could not remember her name or that of the advocacy organisation, he understood that she was ‘fighting his corner’. His memory problems gave particular difficulties when Michael did not recall that his family did not want him to return home, and this information had to be explained to him again in a sensitive manner.

Initially, the advocate tried to advocate informally for Michael, making contact with his family, explaining her role, and suggesting she meet with them to discuss the situation. While the family seemed to want to engage at first, they then declined further meetings or discussions. The advocate liaised with the consultant,
social worker and staff on the ward, who were all supportive of Michael’s wishes. The advocate also contacted the local Law Centre, to clarify Michael’s legal rights.

The family’s position became more entrenched, refusing to attend meetings and pursuing a formal complaint against the health and social care trust. After Michael had been on the ward some months, his family agreed to attend a multidisciplinary meeting and were accompanied to the meeting by their local Member of Parliament. The advocate attended the meeting on Michael’s behalf, and he joined it for the latter part. The atmosphere was tense with Michael being supported to relay his wish to return home. Relationships were clearly strained and at times this meeting was distressing for everyone.

Michael remained on the ward with the family continuing to maintain that they did not want him to return home and liaising with the health and social care trust through their MP. At Michael’s request the advocate contacted a solicitor on his behalf and the solicitor met with Michael and the advocate to explore matters from a legal perspective. The solicitor met with Michael several times, on one occasion accompanied by a medical consultant to conduct a capacity assessment in relation to legal instruction. Both these professionals determined that Michael lacked the capacity to understand the implications of instructing a solicitor. This was a frustrating time for Michael, for the advocate and for the ward staff who felt that the ward was not a suitable place for him indefinitely, with patients constantly being admitted and discharged. It was clear that Michael’s memory problems were increasing.

At this stage the advocate wrote to the health trust and the local MP, outlining the role of an advocate, and highlighting Michael’s rights and entitlements. Some weeks later the family met with the multi-disciplinary team to discuss discharge arrangements, and agreed that he could return home for a trial period.

A number of weeks later the advocate followed up with the social worker who said that Michael was still at home, although relationships with his wife were strained. The social worker said that information and support for his wife in understanding dementia would be welcome. The advocate referred Michael and his wife to the local dementia support worker who gave them help during his initial period at home.

In this case advocacy achieved what Michael wanted: to return home. With the help of supervision the advocate was able to remain focused on Michael’s needs and wishes, whilst recognising the family’s concerns and issues. A wider impact of the case has been that the health professionals involved in the case have recognised the benefits of independent advocacy provision for people with dementia and are continuing to make referrals.

The advocate made several visits over 10 months
**Norman**

still able to enjoy life

The advocate was unable to help Norman find another care home to live in but was able to resolve some issues that made his current home a much better and happier place for him. The advocate demonstrates how person-centred care can make such a difference to a person’s life.

Norman is in his late seventies, originally from the Caribbean, and has been living in a nursing home for nearly five years. He has a diagnosis of severe dementia. Referral for advocacy came as result of an outreach visit to the home by a staff member from the advocacy service. Norman spoke of his desire to move to a smaller nursing home as he found the current one to be too large and impersonal and was told he could be assigned an advocate to support him through the process of finding out whether moving to a smaller home was possible and, if so, deciding where. Norman agreed to this.

On the advocate’s first visit she began explaining her role but it became immediately apparent that Norman did not recall his earlier conversation about wishing to move to a smaller home and that he lacked the capacity to instruct. The advocate spent the session getting to know him, finding out indirectly what he thought about his nursing home. He didn’t give a direct opinion but said that he didn’t think he needed to be there and that he wanted to return home.

However he was clear that if he were to move he wished to stay in the area as he had friends and family locally.

Over a number of visits the advocate found that asking Norman whether he would like to move to a different area of the home to chat often encouraged him to become more talkative. For example, he was often sitting in the communal area of the home when the advocate arrived and asking him if he would like to move to his bedroom, outside or even to the kitchen to make a cup of tea seemed to spark conversation and energy into the meetings. He spoke very slowly and at times did not respond to questions. It took a little while for the advocate to realise that during the silences in the conversation he was organising his thoughts and words so that he could respond to a question or initiate another conversation.

During the first visit the advocate was aware of an overwhelming smell of urine and a badly stained carpet in Norman’s bedroom. Towards the end of the visit he apologised for the smell and was visibly distressed: the advocate asked whether he would like her to speak to the staff about this. Norman was a little diffident but said she could if she wished. The advocate spoke to the nursing home staff: they responded that Norman often said things that he didn’t mean due to his confusion. They said this issue had been raised with the manager of the home some time ago who had assured them the carpet

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13. Four key elements of person centred care comprise the VIPS model: Valuing people with dementia and those who care for them (V); treating people as Individuals (I); looking at the world from the Perspective of the person with dementia (P); and a positive Social environment in which the person living with dementia can experience relative well being (S). Dawn Brooker. Bradford Dementia Group Good Practice Guide
would be replaced with laminate flooring but so far nothing had been done. The advocate spoke too to his nephews who visited occasionally and were aware of the problem.

The advocate investigated the process involved in moving to a different nursing home and established that there was no smaller nursing home in the area, meaning that Norman would have to move away. Meanwhile she contacted the manager of the home about the smell in Norman’s room: it took several emails and phone calls over nearly four months before the floor surface was replaced by lino.

During following visits, the advocate attempted to further explore Norman’s dissatisfaction with his current nursing home. He now said that he was happy where he was: the advocate attributed this to the fact that changing would mean moving away. Norman preferred to talk about other things: his family, favourite foods and musicians. While pursuing the flooring issue she also suggested to staff that Norman’s jazz music could be played sometimes and was assured that this would happen. The advocate noted that staff appeared uninterested in dealing with issues other than residents’ most basic physical needs. There were photos of family members and friends in his bedroom and looking at these encouraged Norman to become more animated as did playing his jazz CDs. His body language changed immediately from sitting with head hung low and eyes closed to sitting bolt upright with eyes wide open. The advocate investigated whether there were local charities to bring older people and music together. There was nothing in place but the advocacy service is currently investigating whether it is possible to arrange concerts for older people in care homes.

On this occasion it was not possible to resolve Norman’s initial issue of moving to a smaller care home but advocacy uncovered another issue, with his bedroom carpet eventually being replaced with a laminate floor that was easier to keep clean and sweet smelling. Playing Norman’s jazz gave him pleasure and he was also benefiting from having someone to talk to. At the advocate’s final visit he surprised her by mentioning something said much earlier in their contact.

More widely it is to be hoped that drawing attention to Norman’s needs had some impact on the staff attitudes in general. Another resident’s flooring was replaced at the same time.
Penny
no longer ignored

The advocate supports Penny to resolve issues around her power of attorney and will, challenges views regarding her mental capacity and addresses financial abuse.

Penny is in her 70’s. She has various health issues, including short-term memory loss due to dementia. This resulted in her having to give up independent living to move into a residential home. At her request, two separate attempts had been made for her to move back home but each time she returned to residential care, mainly because she missed the interaction with people within the communal setting.

In her daily affairs Penny had capacity to make all her own decisions. Her memory problems fluctuated but a lot of the time she was able to make considered choices and statements about what she wanted.

Penny asked for advocacy support as she felt others were taking control of her life and possessions and no-one was listening to her concerns.

Penny asked for advocacy support as she felt others were taking control of her life... and no-one was listening to her concerns

Penny told the advocate that her chief concern was that a relative, who held her Enduring Power of Attorney, had apparently removed items from her home. A health worker involved with the client was concerned and raised a safeguarding alert but no police action was taken. However, the same relative also took over further control of her old home and moved his own family in. He had transferred all the rights to this property to himself - Penny maintained she had no knowledge of the transfer document or any memory of signing it. Penny was angry with her relative but did not wish to involve the police.

Penny was also concerned that a draft will had been prepared at her request some twelve months earlier but due to Penny’s health problems the solicitor was reluctant to proceed with the signing without a medical witness being present. The matter had not progressed since the previous year. Conversations with Penny were not difficult and the advocate soon gained Penny’s trust. There were occasional ‘blank’ lapses when she lost concentration but the advocate gave her time to refocus.

It was agreed with Penny that the advocate would support her in addressing the situation with the relative, changing her Power of Attorney and also making a new will. This involved the advocate meeting with family solicitors; attending a case review with residential home staff, family members and mental health workers; making phone calls; preparing and sending letters; researching Penny’s rights and relevant legislation; and then liaising with the Social Services Safeguarding of Vulnerable Adults Team, her GP, the Mental Health Treatment and Assessment Unit, the residential home and her solicitor.

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14. In 2006 a study found that 7% of adult safeguarding referrals from residential homes concerned financial abuse. Short changed: Protecting people with dementia from financial abuse Alzheimer’s Society 2011
The advocate talked to Penny’s solicitor about her rights under the Mental Capacity Act to assessment of her capacity to make specific decisions. The solicitor agreed to conduct a capacity assessment of Penny prior to the signing of any documents. The result was that Penny was given time and the opportunity to state her wishes and for them to be recorded. As already highlighted by the advocate, Penny’s current expressed wishes fully concurred with her instructions given twelve months earlier. The solicitor ultimately accepted that she was in fact able to make these decisions and was consistent in her wishes. A new will was drawn up and signed.

Penny also instructed that the Enduring Power of Attorney should be revoked and the process was started to confirm someone else of her choosing to have Power of Attorney. Additionally, Penny’s residential home, Social Services and the local SOVA team are now aware of the concerns regarding Penny’s relative and will put in place all appropriate safeguards if contact is maintained.

More broadly Penny has peace of mind about her home ownership and control of her affairs. Additionally awareness among the services and people around Penny has been raised and this should ensure that she will be protected from further abuse.

When Penny first became involved with advocacy she was being disempowered and ignored. Her Advocate made sure she was listened to, had her rights acknowledged, her wishes fulfilled and practical steps taken to help with her problems.

The advocate visited 10 times over a period of 18 months plus four attendances at the solicitors.
Samira
challenging people and procedures

Poor communication and service from several services and professionals meant that Samira and her daughter were struggling. They needed the advocate to persist on their behalf and challenge poor practices.

Samira is a 78 year old Iranian lady. She is at a late stage in dementia and also has physical health problems including a trapped nerve in her spine giving her a lot of pain. Samira lives in a privately rented flat and has care both from her daughters and from care support workers. Referral for advocacy came from a friend of the family who is also a care worker. Advocacy was sought specifically for help with increasing Samira’s care package of 17.5 hours a week.

All visits took place in her own home with Samira’s daughter always present. Samira has now lost the ability to communicate in English, and even in Farsi has only a few words. It is difficult to know how much she understands and she does not always respond appropriately. Just before the advocate first visited Samira had spent some time in hospital and her needs had dramatically increased with two carers needed for personal care. The advocate was told that though Samira was eligible for nursing care both she and her daughter had previously expressed a wish for her to be cared for in her own home.

It was very difficult for the advocate to communicate directly with Samira who was not able to understand her situation. She was distressed and in pain due to the trapped nerve and would scream constantly throughout the advocate’s visit. While Samira’s daughter translated basic information to her mother and the advocate mainly observed and talked with the daughter. Samira’s daughter understood her needs well and was able to calm her down.

The advocate explored the use of visual aids for communicating directly with Samira but this would have been difficult on the issues involved so the advocate asked the daughter to summarise for her mother. Although the advocate was unable to engage with Samira she would greet the advocate with a smile and say thank you after a visit. It was clear there was a strong relationship between mother and daughter: the advocate could see the qualitative difference in the way they communicated comparing it with interaction with the carers.

There were multiple issues for the advocate to address with the family.

- **Safeguarding issues:** one carer was using un-prescribed oils rather than the prescription from the doctor and giving “energy treatment” by waving her hands over Samira’s body. There were hygiene issues and the same carer had tried to get Samira’s daughter to lend her £7,000. The advocate raised a safeguarding alert: although no meeting was ever
held to discuss this matter in detail a new provider took over. The new carers are working well and have been more proactive in trying to communicate in Farsi, learning a few words from the daughter.

- **The care package** was a major concern. NHS continuing healthcare funding was obtained including some night time care, resulting in a reduction in tension for the daughter and Samira becoming calmer. Whilst this might have happened anyway, Samira’s daughter says she feels advocacy speeded the process.

- **Access**: Samira’s flat is not accessible by a lift and she must be physically lifted down the steps when she needs to go out. She has been assessed for a ramp but there are conflicting views as to its feasibility: a permanent ramp cannot be fitted as it affects other residents. The advocate is progressing these discussions.

- **Pain management**: Samira was referred for an anti-inflammatory injection for her spine to relieve the pain but then told she couldn’t have it. The advocate arranged a meeting with the consultant who explained the problem and Samira has now been referred to a pain management clinic and given a morphine patch which has really helped. The daughter just wasn’t having things explained to her and it needed the advocate’s intervention for this to happen properly.

- **Cockroaches were intruding from a neighbouring property**: the advocate organised a visit from environmental health.

In all these matters communication has been a major issue: the daughter feels that many people have not communicated well with her. Her mother was diagnosed very late with dementia probably because the other problems overshadowed the dementia but then the consultant who diagnosed dementia didn’t inform the GP. A psychiatrist came to assess and didn’t inform the daughter of the result. Bed rails were ordered and not delivered. Incontinence pads that Samira was allergic to continued to be delivered.

In this case advocacy has supported both mother and daughter. Samira’s daughter was having problems with her own health and memory but says that having an advocate keeping on top of things has helped her and freed her to better fulfil her role as a carer. She says “My mind feels free, clear, because I know I have you.”

The advocate feels that challenging people and procedures has had a real impact, pulling services up for poor practice, insisting on better communication and moving matters on much more quickly. Without advocacy the daughter would still be struggling and Samira’s health affected.

There have been 10 visits over six months, with visits rather longer than normal at 1.5 hours. The case is still open.
William support through several crises

The advocate has provided long-term support to William initially with financial and legal matters following abuse. Support to resolve several practical issues has improved his quality of life and restoring family relationships has helped improve his mental health.  

William is a 72 year old gentleman who has very poor mobility, using a wheelchair outside his home, which he leaves only for hospital or other appointments. He has a diagnosis of vascular dementia. Referral for advocacy was made by Social Services in order to provide help in setting up direct debits for William’s bills.

The advocate visited William in his home and found him sitting watching TV for much of the day, able to move about very slowly. Carers call four times a day to provide meals, medication and personal care. Communication was difficult, due to his dementia: William loses interest very quickly if he does not fully understand what is being said. Conversations needed to be short and to the point otherwise he lost his train of thought, and was easily distracted. However, once he was engaged William was able to give instructions, mainly yes/no in response to questions. The advocate was patient, keeping to one or two short and direct questions per visit. Initially this required regular and frequent visits.

The advocate talked with family members in order to establish the recent events that had caused concern. Two family members William relied on for support had died and there had been allegations of financial abuse made to the local authority. The advocate was not given details but on investigation found evidence of large transactions being withdrawn from William’s Post Office account. The advocate asked William about this but he had no recollection of the transactions or who had withdrawn the money. The advocate reported his findings to the local authority and they called to see William but he did not want action taken and the person who was looking after his money had since died.

The advocate established contact with William’s brother, who lived some distance away. He had taken on the role of supporting William on financial matters. Together, with the advocate working with William, they closed his Post Office account, opened a new bank account, arranged third party appointeeship and set up direct debits. William’s brother now monitors his account on-line and contacts the advocate when discrepancies occur.

The advocate has helped William with a wide range of other very practical issues including applying for the care component of the Disability Living

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16. “Once you have met one person with dementia you have met one person with dementia.” Quote attributed to the late Tom Kitwood.

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stories of dementia taking their side: fighting their corner
Allowance, arranging with a solicitor for William to make a will, changing the telephone and cable contract to reduce costs, obtaining a wheelchair, commode, applying for a community care grant, buying a new washing machine. Putting William’s Council Tax onto direct debit has averted a costly summons process for the Local Authority. Occupational Therapy assessment of access to the flat is awaited and this will allow William to go out on a regular basis. The family locally no longer has access to his money and William has a managed budget with his capital deposit in the bank gradually growing. If he needs money or goods his brother sends them through the post to the advocate to be delivered in person.

However there were many other family issues that the advocate has helped to address. William has a daughter, Gemma, who lives nearby and has a history of drug and alcohol addiction. Despite her problems, William wants his daughter in his life, even though this is not what other family members want. William’s anxiety over Gemma causes him to not eat properly. Another family member was attempting to get an injunction put into place against Gemma visiting William and the landlord too threatened such action. The advocate pointed out that they were not following procedures set out in the tenancy agreement and liaised with the housing association regarding the complaints raised against the daughter: they decided not to take the matter further. The advocate has supported both William and his daughter through a number of crises and family conflicts, including helping with access to Gemma’s son, William’s grandson, who is in foster care. William is gradually getting out a little more too, as he wishes.

Advocacy has transformed William’s life financially, putting him on an even keel and preventing financial abuse. William has also been helped to expand his horizons with his carers now able to take him out. The advocate is also helping to stabilize a set of dysfunctional family relationships and through the advocate’s support to Gemma William is no longer so anxious about what is going on in her life. Since his daughter has got her life back in order William has put on a stone in weight.

The case is still ongoing with William being supported for 17 months so far.
Glossary

**Advocacy** is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice – Advocacy Charter 2002. Advocacy is provided by a variety of organisations, some small and independent, others larger with a presence in different areas, and others part of a larger organisation providing other services. There is a legal right to advocacy in some specific circumstances (see IMCA & IMHA below)

**Appointeeship** - an appointee is a person who is responsible for managing the welfare benefits of another, if that person (referred to as a ‘patient’) is deemed incapable of managing their own benefits.

**Befriending** is a voluntary, mutually beneficial and purposeful relationship in which an individual gives time to support another to enable them to make changes in their life. It can cover a range of supportive and purposeful activities involving the development of a relationship in which someone who is not family or a close friend, who gives time to support and encourage another person. In relation to people with dementia the likely focus is building trust, alleviating loneliness and social isolation and providing stimulus.

Both **advocacy** and **befriending** aim to build supportive, trusting relationships over time and both include social elements. The main difference is in the aims. Advocacy focuses on having the wishes and needs of the person heard and empowering them to exercise as much control as possible in decisions about their life, while befriending tends to be a more informal, supportive relationship, often over a longer period of time, aiming to increase the opportunities for someone to become more connected to their local community.

**Best Interests** – anything done for or on behalf of people without capacity must be in their best interests. The Act provides a checklist of factors that decision makers must work through in deciding what is in a person’s best interests. A person can put their wishes and feelings into a written statement if they so wish, which the person making the determination must consider. Also, carers and family members have a right to be consulted.

**Care package** is the term used to describe the support from health and social care that might be provided to someone to enable them to stay in their own home when they are unable to fully care for themselves e.g. homecare, daycare, respite.

**Dementia** describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. The symptoms arise when the brain is damaged by certain diseases, the most common form is Alzheimer’s disease which is generally a slowly progressing disease, followed by Vascular dementia which is caused by strokes.
Independent Mental Capacity Advocate (IMCA) is someone appointed to support a person who lacks capacity but has no one to speak for them in connection with important decisions made by the NHS and local authorities about serious medical treatment and changes of residence (for example, moving to a hospital or care home). NHS bodies and local authorities have a duty to consult the IMCA in such decisions involving people who have no family or friends. The IMCA makes representations about the person's wishes, feelings, beliefs and values.

Independent Mental Health Advocates (IMHA) - under the Mental Health Act, some people who use mental health services have a statutory right to access an IMHA e.g. those who are detained in hospital. IMHAs support people to obtain information, understand their rights and the processes around their detention, enabling them to participate in decisions being made.

Lasting Powers of Attorney (LPA) – the Mental Capacity Act allows a person to appoint an attorney to act on their behalf if they should lose capacity in the future. This is a legal process by which an individual gives another person or persons the power to decide what is done with their financial affairs and property or about particular health and welfare decisions. The person appointed is known as the ‘attorney’ and the person giving the power is known as the ‘donor’.

Mental Capacity is the ability of a person to make decisions. This is not a general ability to make decisions but according to each decision that needs to be made at a specific time.

The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who may not be able to make their own decisions. It makes it clear who can take decisions in which situations, and how they should go about this. It also enables people to plan ahead for a time when they may lose capacity.

The Mental Health Act 1983 (England & Wales) provides the legislation by which people diagnosed with a mental disorder can be detained in hospital or police custody and have their disorder assessed or treated against their wishes, unofficially known as "Sectioning" as the Act is divided into Sections. The Act has been significantly amended by the Mental Health Act 2007.

NHS Continuing Healthcare - is a package of care provided outside hospital for people with ongoing healthcare needs. The care package is arranged and funded solely by the NHS and provided by health and social care professionals. Care is provided over an extended period of time to meet adults’ physical or mental health needs caused by disability, accident, chronic illness or following hospital treatment. The individual would be assessed to see whether they are eligible.
Sectioning under the Mental Health Act – the Act is divided into Sections dealing with specific situations eg. Section 2 is an assessment order and lasts up to 28 days; it cannot be renewed. Section 3 is a treatment order and can initially last up to six months.

Safeguarding of Vulnerable Adults (SOVA) is the process of protecting those who are vulnerable to abuse or mistreatment. A vulnerable adult is a person aged 18 years or over who may be unable to take care of themselves; or protect themselves from harm; or from being exploited.

Safeguarding of Adults Alert is the term used to describe the reporting of suspicions or allegations of harm or abuse of a person who is an ‘adult at risk’ to Adult Social Care Services. Once an alert has been made, Adult Social Care Services will undertake initial checks and assess the seriousness of the reported information. A decision will then be made about whether the concerns identified in the alert should be investigated under the Adults Safeguarding Procedures.
For any further information please contact us at:

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The Dementia Advocacy Network is an arm of Advocacy Plus (London) Ltd, a registered charity, providing independent advocacy services and support for older people locally and nationally.

For more information about Advocacy Plus please call 020 7837 6744 or email info@advocacyplus.org.uk

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