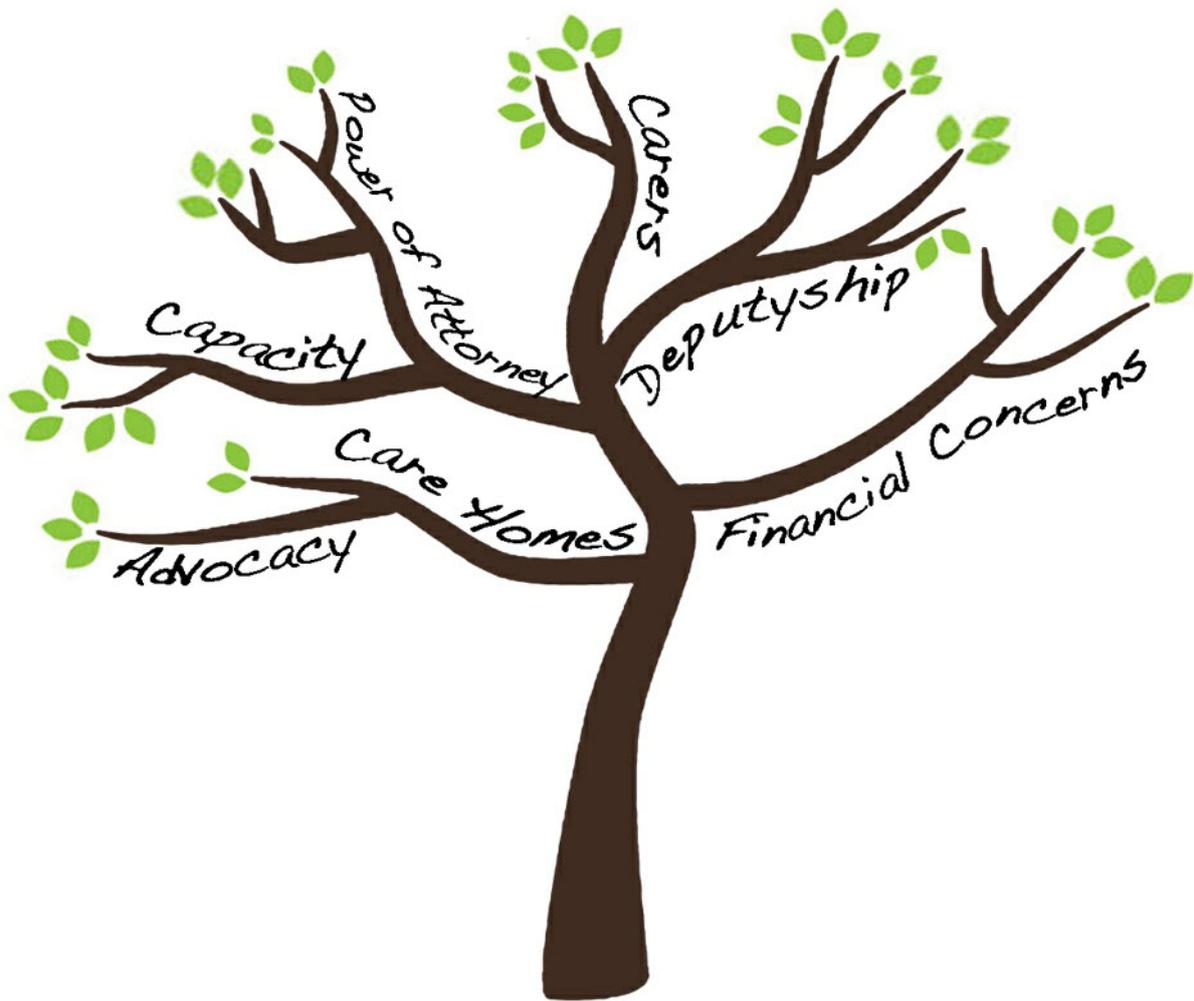


Advocacy: Speaking up for you



AGE concern
Cardiff & The Vale of Glamorgan

 **age Cymru** Gwent

AGE concern
Morgannwg Ltd

AGE concern
Torfaen



ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

Foreword

The South East Wales Safeguarding Older People project is a partnership project providing independent advocacy services. The project operates across nine local authorities and three local health board areas in the South East Wales region. The project received Big Lottery Fund AdvantAGE Programme funding of just under £1 million to deliver advocacy support to older people until November 2014.

The project is essentially a programme coordinating 4 'local' projects that all provide advocacy services which empower and promote the views, voice and rights of vulnerable people aged over 50. Across the region, the project employs a team of 10 Advocacy Caseworkers and a Regional Advocacy Manager.

Age Concern Cardiff and the Vale of Glamorgan - provides support to older people who have dementia and are living in a care home setting.

Age Concern Morgannwg - provides support for people who are experiencing any issues and are living in, or considering a move into, a residential or nursing home, sheltered housing complex accommodation or are requiring support with accommodation when being discharged from hospital.

Age Concern Torfaen - provides focused advocacy support to people aged over 50 who live in any setting within Torfaen.

Age Cymru Gwent - provides support for people who are experiencing financial difficulties. This may be due to a decreased ability to manage finances independently, a significant change in financial situation, a potential change in financial situation or risk of financial abuse.

This booklet consists of a series of real case studies that have been provided as examples of the advocates' work and demonstrates the wide range of issues they deal with. It aims to demonstrate the value of advocacy in a variety of different situations in an accessible format.

Advocacy supports people and can help them to grow and flourish. It can plant the seeds that can empower them to help themselves in the future. Therefore, a tree image has been used throughout this booklet to portray the nature of advocacy.

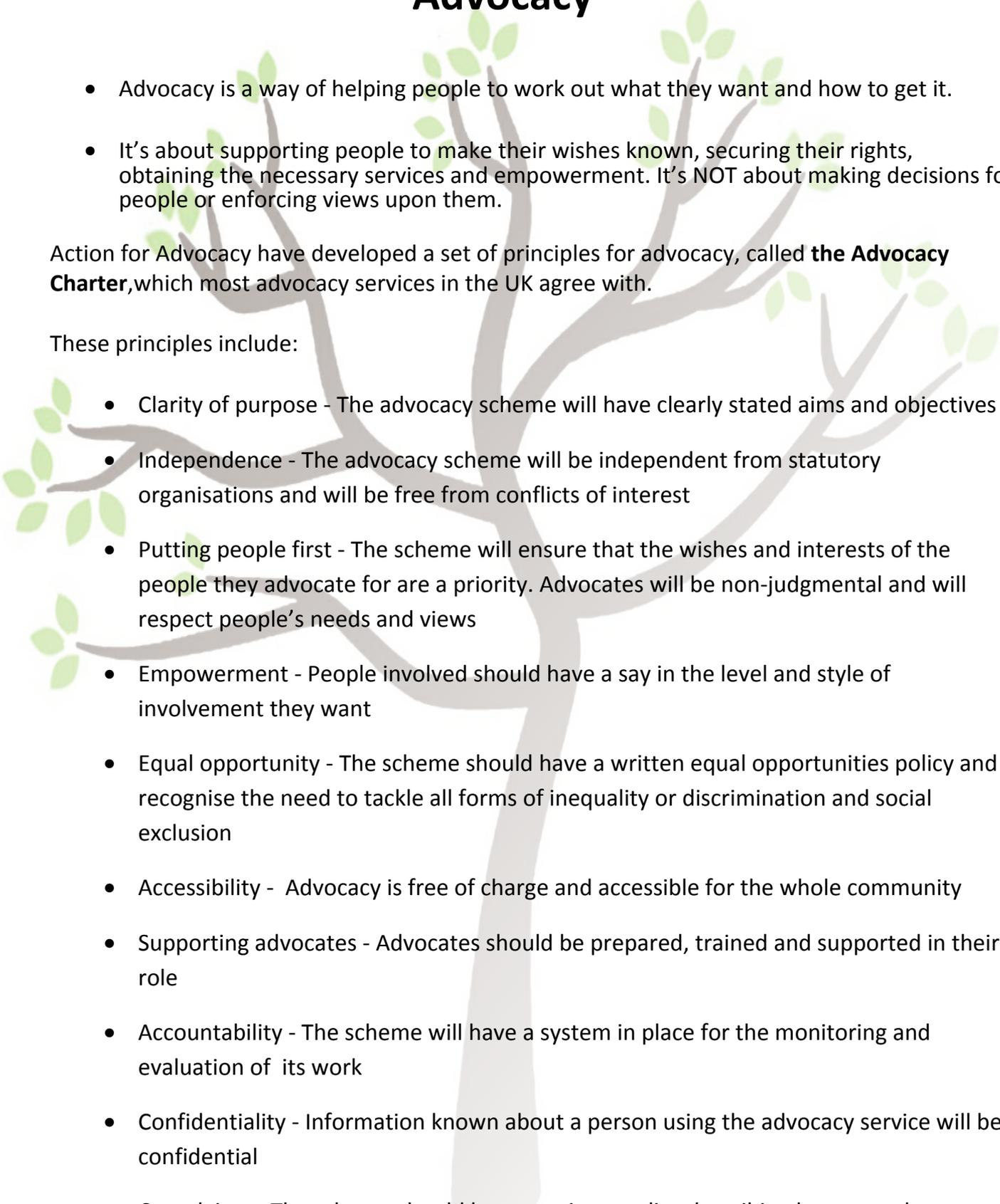


Jeff Hawkins
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Advocacy



- Advocacy is a way of helping people to work out what they want and how to get it.
- It's about supporting people to make their wishes known, securing their rights, obtaining the necessary services and empowerment. It's NOT about making decisions for people or enforcing views upon them.

Action for Advocacy have developed a set of principles for advocacy, called **the Advocacy Charter**, which most advocacy services in the UK agree with.

These principles include:

- Clarity of purpose - The advocacy scheme will have clearly stated aims and objectives
- Independence - The advocacy scheme will be independent from statutory organisations and will be free from conflicts of interest
- Putting people first - The scheme will ensure that the wishes and interests of the people they advocate for are a priority. Advocates will be non-judgmental and will respect people's needs and views
- Empowerment - People involved should have a say in the level and style of involvement they want
- Equal opportunity - The scheme should have a written equal opportunities policy and recognise the need to tackle all forms of inequality or discrimination and social exclusion
- Accessibility - Advocacy is free of charge and accessible for the whole community
- Supporting advocates - Advocates should be prepared, trained and supported in their role
- Accountability - The scheme will have a system in place for the monitoring and evaluation of its work
- Confidentiality - Information known about a person using the advocacy service will be confidential
- Complaints - The scheme should have a written policy describing how to make complaints and give feedback about the scheme or individual advocates

Joan's Diary

18th August

I am unsure what to do. Today, I received news that my husband, Thomas, is fit to be discharged from hospital. I don't think I can cope if he comes home. For years, I have put up with his abuse and, more recently, his declining health but I no longer feel I am able to deal with it. The people at the hospital think Thomas should go to into a care home but he's adamant he wants to come home.

Staying with my dear friend, Margaret, has been a great help to me. I am scared of going back home, of having Thomas at home, of dealing with the stress of looking after him and being subjected to his insults.

23rd August

The Carers Centre have put me in touch with an advocate called Claire from Age Concern. She rang Margaret's house today. I didn't feel confident enough to speak to her, so Margaret spoke on my behalf. I told her to tell Claire I want her help.

25th August

Claire visited today. She was very friendly and put me at ease. I told her that I had contacted a care home who are willing to assess Thomas. Claire agreed to make some enquiries with the hospital and speak on my behalf. I broke into tears. I couldn't help myself as it's such a relief to have someone helping me.

Although this is for the best, I feel guilty about sending Thomas to a home. I don't know if he'll be able to cope by himself and I feel, as his wife, I should be looking after him. I just no longer can.

7th September

Claire telephoned today. She contacted the hospital and was told Thomas had been abusive towards staff. She also told me there had been a meeting discussing discharge arrangements for Thomas. Claire had told them of my wishes and Thomas had realised he would not be able to cope at home alone.

20th September

Thomas has been accepted into a care home! I'm so relieved. I have my life back and I can see my friends whenever I like. Margaret and I have plans to go to the theatre next week.

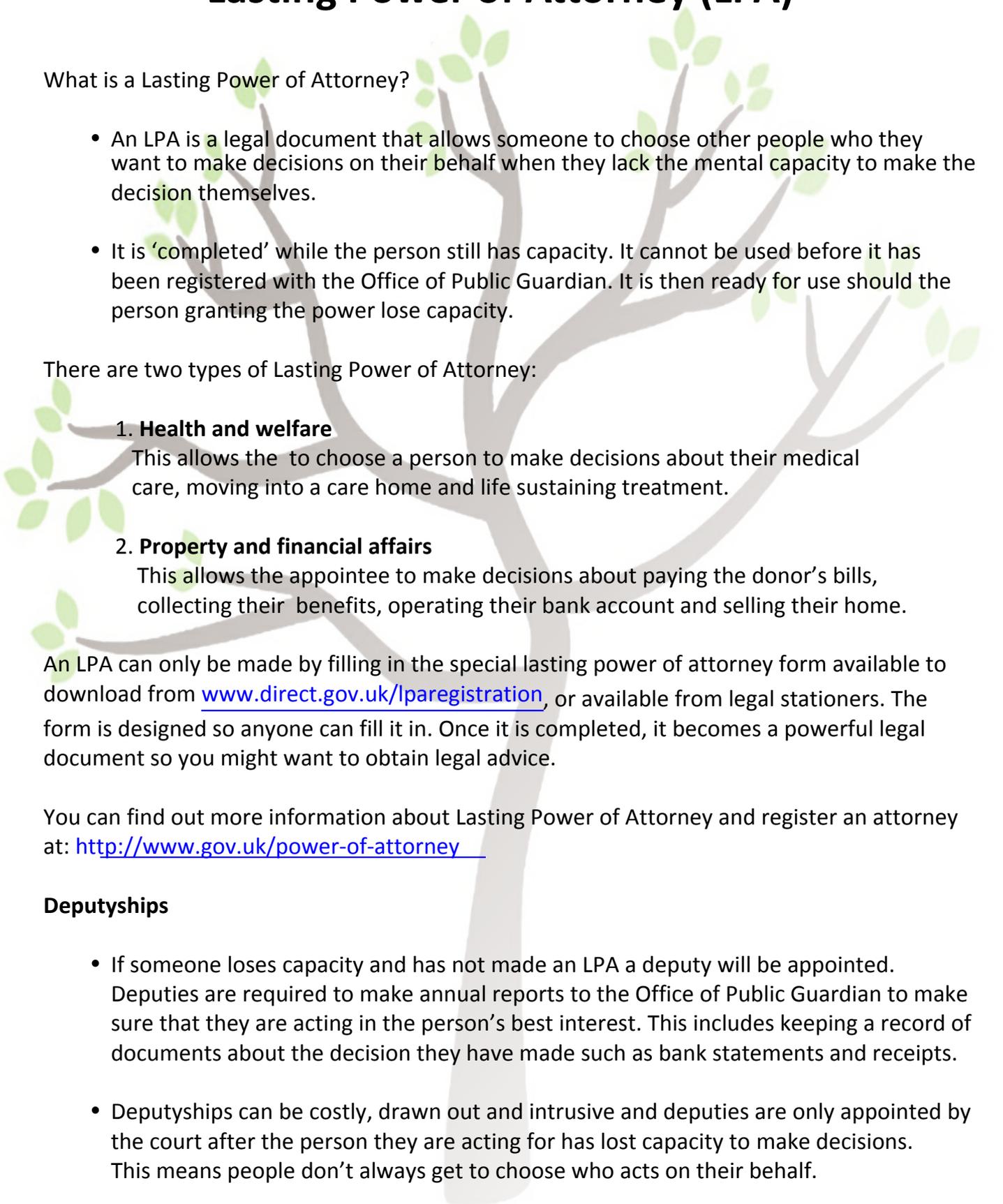
2nd November

Thomas is back in hospital with a chest infection but this is not the worst news. Before he was taken to hospital, he was abusive towards staff at the care home and even assaulted a carer – now they're saying they can't take him back when he is discharged. I thought all this was behind me. I've made a decision, I am going to visit Thomas and tell him how I feel. I am very scared as I've never had the courage to stand up to him before.

6th November

Claire and I visited Thomas in the hospital. It was such a relief when Claire said she could come with me. It made me feel strong enough to confront him. I told Thomas I could no longer live the way I had. It was very emotional and I got a lot of things off my chest. Finally, he agreed a new care home should be found. Claire called some care homes for me and explained the situation. One home agreed to take Thomas on a trial basis. This is such good news. Now I have told Thomas how I feel, hopefully he will make more of an effort at this home. I am so grateful to Claire.

Lasting Power of Attorney (LPA)



What is a Lasting Power of Attorney?

- An LPA is a legal document that allows someone to choose other people who they want to make decisions on their behalf when they lack the mental capacity to make the decision themselves.
- It is 'completed' while the person still has capacity. It cannot be used before it has been registered with the Office of Public Guardian. It is then ready for use should the person granting the power lose capacity.

There are two types of Lasting Power of Attorney:

1. Health and welfare

This allows the donor to choose a person to make decisions about their medical care, moving into a care home and life sustaining treatment.

2. Property and financial affairs

This allows the appointee to make decisions about paying the donor's bills, collecting their benefits, operating their bank account and selling their home.

An LPA can only be made by filling in the special lasting power of attorney form available to download from www.direct.gov.uk/lparegistration, or available from legal stationers. The form is designed so anyone can fill it in. Once it is completed, it becomes a powerful legal document so you might want to obtain legal advice.

You can find out more information about Lasting Power of Attorney and register an attorney at: <http://www.gov.uk/power-of-attorney>

Deputyships

- If someone loses capacity and has not made an LPA a deputy will be appointed. Deputies are required to make annual reports to the Office of Public Guardian to make sure that they are acting in the person's best interest. This includes keeping a record of documents about the decision they have made such as bank statements and receipts.
- Deputyships can be costly, drawn out and intrusive and deputies are only appointed by the court after the person they are acting for has lost capacity to make decisions. This means people don't always get to choose who acts on their behalf.

Joyce's story

“Edith, it's me, Joyce” I say, pulling up a chair. Edith opens her eyes and smiles fleetingly before closing them again. “Oh, Edith” I whisper. I remember Edith as she was when we first met, such an independent, clever lady, so quick-witted and bright-eyed; I was marrying her younger brother, Johnny, and was so eager for her to like me, for us to be friends and we were. Johnny died several years ago and Edith's husband passed away shortly after. Edith and I had stuck together during that difficult time but slowly Edith's health had deteriorated too and dementia had taken over. Now, I am Edith's Deputy, taking responsibility for her financial affairs and making decisions I feel she would make, if able.

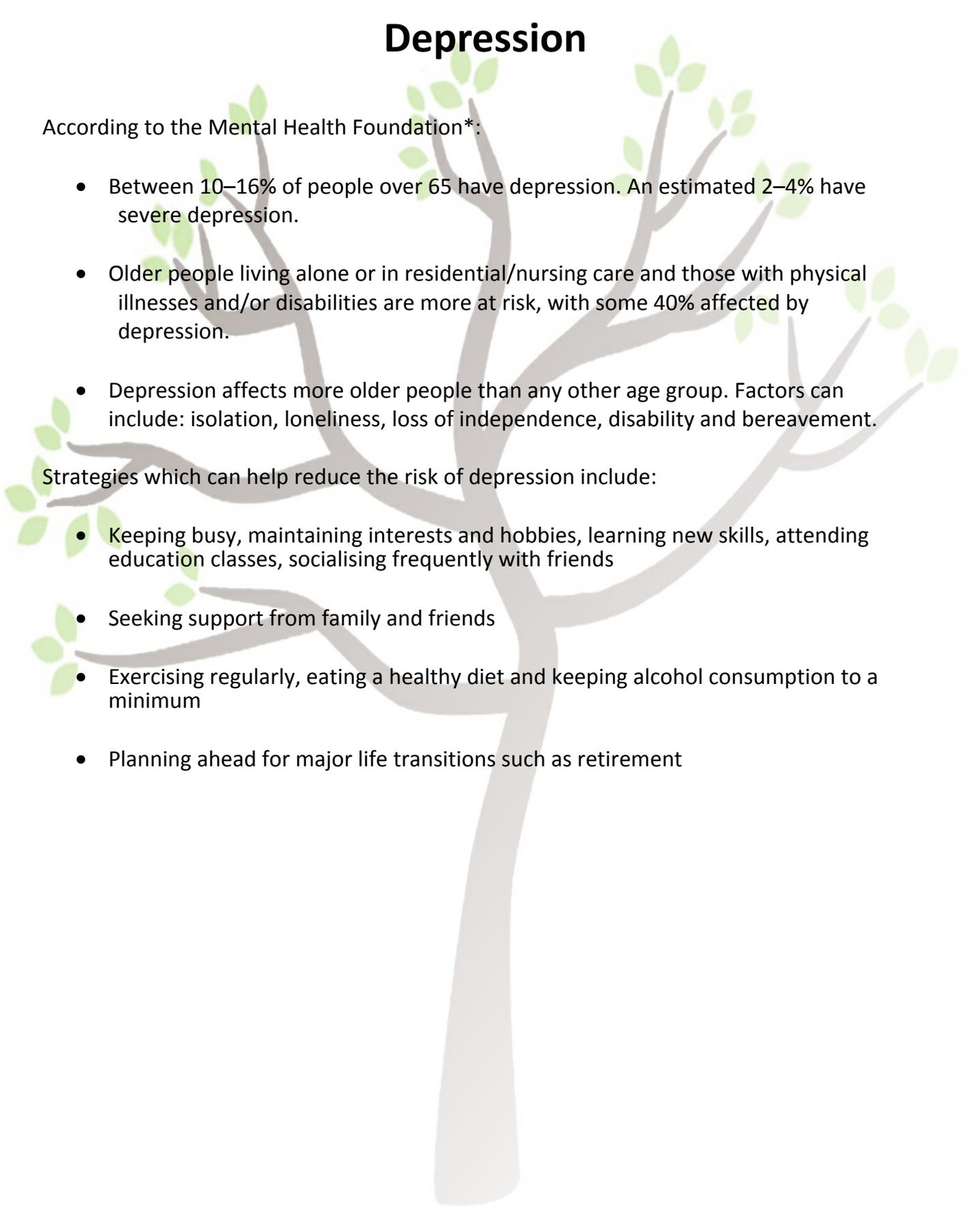
I watch silently as she sleeps in her chair. Edith had a respectable job in the civil service and had made good provision for her retirement but I had noticed the funds she had saved to pay her care home fees were rapidly diminishing. This was causing me concern as I want to do my best for Edith and make sure she has the best care but I am worried how the fees will be paid when her money runs out. I slip away to make a telephone call, while Edith sleeps. I have heard about the Age Concern Advocacy Service from a friend and want to see if they can help me. They put me in touch with an advocate, Cathy, who agrees to visit me and Edith.

Several days later, Cathy is sat with us at the home. I show her Edith's financial statements and she agrees that Edith's financial position is, indeed, a concern and says a full financial assessment is necessary. Cathy explains the process for a financial assessment and gives me the telephone number for the local authority finance department. Cathy also makes arrangements for me to meet with Edith's social worker. Cathy explains that she personally has little practical knowledge of the management of funding care but that her colleagues are offering her lots of support and advice on the matter and she is confident it will be quickly resolved. She offers to make some telephone calls to the appropriate authorities to get the ball rolling. This is a relief; I was worried I would have to deal with this all by myself. I now have lots of support and advice.

Edith's social worker and the finance department quickly get on the case and draw up a plan ensuring Edith's fees will continue to be paid through a combination of her pension fund and the local authority paying the rest. This is such good news but I still have a nagging concern I want to discuss with Cathy; as part of my role as Deputy for Edith, I have to complete forms for the Office of Public Guardianship, proving I have been managing her financial affairs appropriately. I feel unable to fill in these forms alone as they are confusing and time-consuming to complete and require me to check a year of bank statements and verify all the transactions. It seems such a daunting task and thinking about it makes me feel anxious and overwhelmed.

I decide to contact Cathy and ask for her help. She agrees and the next day we are sat pouring over the forms, cups of tea in hand, checking this and verifying that. When we eventually complete the forms, I feel light with relief. “Thankfully everything has been sorted now” I tell Edith. Although she is unable to speak, she smiles and nods and I know she is as pleased as I am.

Depression



According to the Mental Health Foundation*:

- Between 10–16% of people over 65 have depression. An estimated 2–4% have severe depression.
- Older people living alone or in residential/nursing care and those with physical illnesses and/or disabilities are more at risk, with some 40% affected by depression.
- Depression affects more older people than any other age group. Factors can include: isolation, loneliness, loss of independence, disability and bereavement.

Strategies which can help reduce the risk of depression include:

- Keeping busy, maintaining interests and hobbies, learning new skills, attending education classes, socialising frequently with friends
- Seeking support from family and friends
- Exercising regularly, eating a healthy diet and keeping alcohol consumption to a minimum
- Planning ahead for major life transitions such as retirement

*<http://www.mentalhealth.org.uk/help-information/mental-health-a-z/O/older-people/>

Zena's dairy

18th March

Recovering from this operation is harder than I thought it would be. I am constantly tired and down and don't feel like getting up most days. I haven't left the house in weeks and feel unable to ask my daughters for help, as we barely speak these days.

20th March

I received a letter today saying my Disability Living Allowance has been reassessed and my benefit has been removed. I feel too distressed to deal with this right now. I might just go back to bed.

22nd March

I've decided to summon what little fight I have left in me and appeal the decision regarding my Disability Living Allowance. I've contacted the Age Concern Advocacy Service as I feel I can't deal with this by myself. They're sending someone to visit me soon. I am nervous about meeting her, I hope she's friendly.

25th March

The lady from Age Concern visited me at home today. Her name is Sara. I am not sure yet whether I can trust her but she seems nice. It was good to have someone to chat to and being asked how I am coping. Sara was very helpful and told me lots about the appeal process. I am slightly less nervous about attending the appeal now as I now know what to expect. I am still very scared though; I am not sure I have it in me to talk in front of everyone.

27th March

Since Sara's visit I am feeling a little bit more positive. I woke up today feeling more in control and decided to clean my house and sort out all my paperwork ready for Sara's next visit. I've also decided to go back to my craft class.

30th March

Sara came round again today. She gave me some more information about the appeal and then made some phone calls on my behalf. She also asked if I would like to make some calls, with her there for support. I was worried at first, but Sara helped me if I got flustered and talking to people on the phone wasn't as scary as I thought it would be. I am so glad I pushed myself and am starting to feel that maybe I am strong enough to fight this appeal after all.

10th April

Today was the day of the appeal. Sara came with me to offer support and prompt me when I became anxious. I am so proud of myself for attending the appeal and standing up for myself. I couldn't have done it without Sara's help. As a result, my Disability Living Allowance has been reinstated but at a reduced amount. I feel happy about this but a bit worried about how I am going to budget.

12th April

Sara visited today and together we put together a budget sheet. Sara also arranged for some repair work to be done on my house and for living aids to be installed, all for free.

5th October

It has been six months since my appeal and so much has happened since. With Sara's support, and the help of other professionals, I have been working to overcome my depression and my relationship with my family has improved. I have also been able to save up for a car and am now able to attend several craft classes all over the city and attend other community clubs and events. I even make handbags and sell them at local fairs. I feel as if my life is back on track and I am able to deal with any obstacle thrown my way.

Protection of Vulnerable Adults

A vulnerable adult is 'A person who is 18 years of age or over, and who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him/herself, or unable to protect him/herself against significant harm or serious exploitation'.*

Types of Abuse:-

- Physical – such as slapping or hitting
- Psychological – intimidation, being threatened, being ignored or preventing family or friends visiting
- Verbal – such as name calling
- Financial – such as stealing someone's money or spending it on the wrong things, putting pressure on someone to change a will or spend their money against their wishes
- Sexual – forcing someone into an unwanted sexual activity or being touched inappropriately
- Neglect – not caring for someone properly, not providing adequate food or putting them at risk
- Discriminatory – when a person is treated unfairly because of their colour, religion, disability or sexual orientation.
- Institutional – such as a rigid and insensitive routines or inadequate privacy or comfort.

If you are alerted to/concerned that a form of abuse has taken place in respect of a vulnerable adult

OR you have personally witnessed some form of abuse towards a vulnerable adult

OR you are told by a vulnerable adult that some form of abuse has taken place towards themselves

OR you receive a direct referral/disclosure from a third party

Act now. Social Services have a duty to look into all referrals they receive. Any person who reports their concerns can be sure that they will be fully investigated and, if appropriate, action will be taken.

*Law Commission - Who decides?: Making decisions on behalf of mentally incapacitated adults 1997

Moira's story

"Please help me. I want to leave this place" Moira pleads with me, her misery is plain. Moira is a temporary resident in a private residential home. She had previously lived alone but has a history of substance misuse and was neglecting herself, her home and her pets.

Moira's social worker had contacted the Age Concern Advocacy Service and I had been appointed to help ascertain Moira's wishes about her living arrangements, as she had been giving mixed messages; telling her social worker she wanted to leave but staff at the home she was happy to stay.

"I think I might just end it" Moira cries. I feel cold with worry but maintain a reassuring expression. "The staff here don't respect me, they treat me like a child" she continues and explains how they open her post and withhold information about appointments until the day arrives, leading to her refusal to attend because she feels unprepared. I lean over and squeeze Moira's arm, "I'm here to help you, Moira" I say encouragingly.

On my way out, I meet with the Home's Manager and tell him I am worried. "That's just Moira" he shrugs and walks off. I am stunned by his lack of sensitivity. Later that day, I discuss my concerns with Moira's social worker and she agrees to draw up a new care plan for Moira, including giving her independence to open her own mail.

Some weeks later, I visit Moira again. "One of the men who works here was shouting at a resident last night" she confides. I urge her to continue. "I also saw him making fun of a man with dementia" she says. "You understand this is serious" I warn her "I'll have to report this to social services". Moira also tells me the staff are still opening her mail. I find the Manager and tell him Moira's care plan means she should be able to open her own post. "She can get lost!" he replies brusquely, attracting the attention of another member of staff. "Like everyone else, Moira is here to be looked after and that includes opening her mail" she nods, agreeing with the Manager.

I decide to raise my concerns about the member of staff Moira mentioned but the Manager is dismissive. "He always speaks like that. He just has a gruff voice" the Manager waves his hand flippantly. I am now seriously concerned. These comments and the attitude of the staff is deeply worrying and alarm bells are going off in my head. Something needs to be done, urgently. "Moira has capacity to open her own mail. The residents should be treated as individuals according to their individual needs, not all the same" I retort.

As soon as I leave, I ring social services and complete a VA1 form, referring the issues to the Local Authority Adult Protection team for further investigation. I also contact the Care Home Inspectorate (CSSIW) and pass on my concerns. They agree to carry out an unannounced inspection of the home. I plan to continue supporting Moira and the other residents of the home through routine visits and observation. I just hope this situation is resolved and it's not as serious as I fear it may be.

Mental Capacity Act

Capacity describes the ability someone has to make a decision and whether they are able to understand the information relevant to make a decision, retain that information, weigh up the pros and cons of a situation, communicate their decision and understand its implications.

The Mental Capacity Act 2005 protects people who lack capacity and ensures their rights are being upheld. The Act outlines five key principles:

- A person must be assumed to have capacity unless it is established they lack capacity.
- All practicable steps must be taken to help a person make a decision and they must only be treated as unable to make a decision when all these steps are unsuccessful.
- Just because a person makes what other people think is an unwise decision, they should not be treated as lacking capacity to make that decision.
- A decision made on behalf of a person who lacks capacity under the Act must be in their BEST INTEREST.
- Any decision made for or on behalf of a person who lacks capacity should be the least restrictive of their rights and freedoms.

The Deprivation of Liberty Safeguards (DoLS) are a supplement to the Mental Capacity Act 2005 and only apply to people who have been assessed as lacking the capacity to consent to the care or treatment they receive. They only apply to people who are:

- Aged 18 or over
- In receipt of care in a hospital or care home
- Deprived of their liberty through the care they receive
- Not detained under the Mental Health Act

Sometimes, deprivation of liberty is in a person's best interest and is necessary to keep an individual safe. If this is the case, the Managing Authority has a legal duty to apply to the Local Health Authority or Health Board for authorisation to deprive someone of their liberty.

Kitty's story

I remember clearly the first time I met Kitty; it was two months ago. It was snowing that day, I remember because there was a big hold up on the motorway and I was worried I wouldn't make my appointment in time. I was interested to meet Kitty and concerned about her situation. The Age Concern Advocacy Service I work for had put me in touch with Vicky, Kitty's daughter, after she had contacted them, voicing concerns about her mother. "My Mum was always such a sociable, independent lady, now there are times I barely recognise her," Vicky had told me, her voice shaking with emotion.

Kitty had been diagnosed with dementia several years ago and had recently been moved into a residential home, after the confusion and disorientation associated with her condition had rapidly increased. However, Kitty had not settled in easily and would isolate herself from staff and other residents, sitting by the front door for hours on end every day, demanding to return to her own home. The Manager of the home had become worried Kitty was being deprived of her liberty and had contacted the Deprivation of Liberty Safeguards (DoLS) team to assess the situation. Vicky had requested an independent advocate be present at all the meetings and for ongoing support for her mother. This is where I came in.

As the snow fell lightly outside her window, laying a crisp white carpet on the lawn outside, I met Kitty and Vicky in her room at the home. I explained I was there to help and chat about how Kitty felt living in the home. She was visibly agitated and adamant to leave. "I'm an independent person and always have been, I don't want to be here, I want to be at home!" Kitty had said firmly, rebuffing any attempts by her daughter to make her understand she may be better off in the home. "Oh shut up, Victoria!" Kitty had hissed at an obviously hurt and exhausted Vicky.

I noticed during the meeting that Kitty seemed to fluctuate between being capable and aware and being confused and frustrated. I decided to do some observational work to see how she interacted with others at the home and what messages her body language was giving. I noticed Kitty was often left alone in her room for long periods of time and little attempt was made by the staff to distract or interact with her. After several visits, I was sure Kitty was miserable and compiled a report of my findings. I then attended a meeting with the care home Manager, social worker and Vicky. I emphasised to others my concern for Kitty and her deep unhappiness in the home. I felt very strongly that I was there to represent Kitty, voice her concerns and make sure her feelings were respected.

I received news last week that the DoLS process has been completed – they found Kitty was being deprived of her liberty but it was in her best interests. However, there will be an ongoing review. I'm not sure how I feel about the outcome because, although it is in Kitty's interests to stay in the home, she is still very unhappy. I have visited her several times since and suggested she write a diary to help with her anxiety. I have also emphasised to the Manager the need for more activities and interaction in the home for patients with dementia, hopefully he will implement some of these suggestions and Kitty's boredom and unhappiness will be alleviated.

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Mental Health Foundation - Older People

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NHS UK - Carers

<http://www.nhs.uk/CarersDirect/carerslives/aboutcaring/Pages/Whatisacarer.aspx>

NHS UK - Mental Health

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-diagnosis- tests.aspx>

Useful organisations

Alzheimer's Society

www.alzheimers.org.uk

Offers support and advice to people with dementia and their families.

CareAware

www.careaware.co.uk/

A non-profit-making public information and advisory service specialising in elderly care funding advice in the UK.

Care and Social Services Inspectorate Wales

www.cssiw.org.uk

If you are considering a move to residential care, each home will have a report by the Inspectorate, which can be viewed on this site.

Counsel and Care

www.counselandcare.org.uk/

Charity giving advice and information to older people, their relatives and carers across the UK.

Carers UK

www.carersuk.org/

For carers nationally, information on legal rights and your local services for carers.

Citizens Advice Bureau

www.citizensadvice.org.uk

Free advice centres offering confidential and independent advice, face-to-face or by telephone.

FirstStop

www.firststopcareadvice.org.uk/

Information service for carers and older people provides advice on care and housing /care homes in later life.

Office of the Public Guardian

www.justice.gov.uk/about/opg

Agency that supports the Public Guardian in the registration of Lasting Power of Attorney and the supervision of Deputies appointed by the Court of Protection.

The Relatives & Residents Association

www.relres.org/

Charity supporting care home residents and their relatives.

Acknowledgements

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