



Dementia: autonomy and decision-making

Putting principles into practice

Research summary and recommendations
for policy and practice



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1 Introduction

Project overview

This report presents the main findings and recommendations from a research project to identify and meet the support needs of lay proxies (that is family members, partners or friends appointed as guardians and attorneys under the Adults with Incapacity (Scotland) Act 2000 or as deputies and attorneys under the Mental Capacity Act 2005, England and Wales). The project focused on those with the responsibility for making decisions and acting on behalf of people with dementia who are no longer able to do so for themselves. In law, proxies must act in accordance with a set of principles which reflect the rights of people who lack capacity, yet they are given little information, support or advice on how to do so.

The research and development project was led by Jan Killeen from Alzheimer Scotland between November 2009 – March 2012. The project had four main objectives: to identify issues facing lay proxies; to identify what they felt would help them as decision-makers for the person with dementia; to identify models of good practice in meeting the needs of lay proxies; to inform and influence policy and practice to ensure lay proxies are empowered to make best interest decisions. The study included lay proxies and professionals in Scotland, England, The Netherlands and Germany. It comprised: small group discussions and interviews with 100 lay proxies; multi-disciplinary roundtable discussions with over 100 professionals; and a worldwide literature search.

A practical guide to decision-making for family members, partners and friends who have powers of attorney, guardianship or deputyship has been published as part of this project. It is informed by the experiences of lay proxies and shows how the principles can be used as a tool to aid good decision-making for the person with dementia. (See inside back cover for how to obtain this free guide).

This report acknowledges recently published research and case based investigations which focus on best practice and compliance with incapacity laws by health and social service professionals. The shared learning from these studies complements this project with its unique focus on the experiences and support needs of family members, partners and friends who act as lay proxies for an individual with dementia.

This report also recognises ongoing work to address policy issues which are central to the human rights agenda, including a forthcoming consultation on the Adults with Incapacity (Scotland) Act by the Scottish Law Commission, the proposals for graduated guardianship initiated by the Public Guardian in Scotland and developments in the respective National Dementia Strategies of the Scottish and Westminster governments.

Summary of key findings

- In the UK there was widespread agreement between lay proxies and professionals that the heavy demands on lay proxies go largely unrecognised and they receive little information, advice or support. There is no statutory duty for lay proxies to be offered training, yet they are required to comply with principles and duties set out in Codes of Practice, of which few were aware.
- In addition, lay proxies face challenges and barriers which arise from policies, procedures and practices which mitigate against their efforts to use their powers in the best interests of the person.

Summary of key recommendations

- Develop and implement a national programme of easily accessible, low cost education to ensure lay proxies are well informed and empowered to apply best practice in decision-making.
- Local authorities, with health boards, to revise and update knowledge and skills of health and social workers on incapacity and related legislation; the central role of welfare proxies in capacity assessment, supported decision-making and care planning.
- Newly appointed proxies to receive a copy of the appropriate code of practice and information about relevant guides, cost to be included in the registration fee.
- Government to review provisions and improve guidance to better reflect the United Nations Convention on the Rights of Persons with Disabilities.
- Financial institutions to ensure that their procedures recognise the authority of financial attorneys and guardians/deputies.

Dementia and decision-making

People with dementia have a lifetime's experience of making decisions for themselves; however, dementia is a progressive condition which gradually erodes their capacity to make some or all decisions in their own interests. They lose the memory of recent events and decisions, recognition of people and places and, often, the ability to communicate. For some types of dementia, the onset is more rapid and the changes traumatic. During the course of the illness, individuals lose the ability to make judgements about decisions in the way that they normally would do. They lose the skills needed for making rational, legally binding decisions and managing finances. Their ability to assess risks diminishes to the extent that they may put themselves or others at risk in the environment or at risk of abuse.

The law says that capacity is not 'all or nothing,' that a diagnosis such as dementia does not mean that the person automatically lacks capacity, and that an assessment of capacity must be decision specific. Family members, partners and friends have the complex task of moving between supporting the person to make their own decisions, to making decisions together, and, when necessary, using the powers granted to them, to act as substitute decision-makers. They are faced with the need to understand how and when to intervene. All this in the context of day to day caring.

The gravity of taking on the responsibility of being an attorney, guardian or deputy cannot be underestimated, as it profoundly affects the human rights of the person over whom powers have been granted. In the difficult and complex situations faced by many lay proxies in the UK, there is little support to help them reach decisions in the person's best interests and carry them through.

2 About the law reforms

The Adults with Incapacity (Scotland) Act 2000 (AWI) and the Mental Capacity Act 2005 (MCA) both have at their core a set of principles which recognise the rights of people with impaired decision-making capacity caused by mental illness, learning disability, head injury, dementia or related conditions. These reforms introduced a radical change to the legal concept of capacity, from one which regarded decision-making capacity as 'all or nothing' to one which recognises that capacity is decision specific, relating to the time when a decision or action needs to be taken. The legislation enables the appointment of a person or persons to act or make a decision when the person lacks the capacity to do so in their own interests. Both Acts have a range of provisions. This study focuses on those appointed as attorneys or guardians under AWI and those with lasting powers of attorneys (LPA) and deputies under MCA. However, anyone making best interest decisions under MCA must also adhere to the principles and, in Scotland, the application of the principles is regarded as good practice for professionals supporting people who may lack some or all capacity but do not have a legally appointed proxy.

The principles

The principles encompass the right of the individual to exercise their autonomy as far as possible and require others to support them to do so. The principles must be applied to any decision or action which the proxy is considering on behalf of the person.

The study takes an integrated approach to the principles set out in AWI and MCA as a basis for best practice in decision-making. MCA principles are explicit in relation to supported decision-making, which is helpful. These legal principles are also ethical principles which inform the care and support of persons with dementia and others with incapacity. Most lay proxies in the study were unaware of the principles. In discussion about how they make decisions, it emerged that their common-sense approach reflected the principles and this worked well when matters were straightforward. However, they felt that knowledge of the principles would have been particularly helpful and empowering in the face of challenges by other family members, professionals or other agencies.

The principles

- Assume capacity unless there is evidence to suggest otherwise.
- Don't assume the person lacks capacity simply because they make an unusual or unwise decision.
- The person has a right to be supported to make his or her own decision/s and communicate the decision/s before it is assumed capacity to do so is lacking.

Any decision or action taken on behalf of the person must:

- benefit the person and be in their best interests
- restrict the person's freedom only so far as it is necessary to gain the benefit needed
- take account of his or her past and present views, wishes, values and beliefs
- take account of the views of relevant others (as specified in legislation)
- encourage the person to use his or her abilities and develop new skills.

Statutory duties to support and supervise lay proxies.

Guardians in Scotland:

The local authority has a duty to both supervise and support private (lay) welfare guardians. The minimum requirement is to visit both the guardian and the named individual within three months of the order being granted and make contact every six months thereafter. The Public Guardian has a duty to supervise financial guardians i.e. to ensure they are carrying out their functions properly. This is largely through the requirement for a management plan, annual accounts and permissions regarding specified decisions. An annual fee is charged.

The local authority and Public Guardian collaborate where the person has both a welfare and financial guardian.

Deputies in England and Wales:

The Public Guardian's statutory role includes supervision of decision-making by deputies appointed by the Court of Protection. There are four levels of supervision for deputies depending on:

- the complexity and value of funds involved
- the type of decision
- the support available from elsewhere
- the specific circumstances (the OPG may be asked to monitor by the Court of Protection).

An assessment is required to see what level of supervision will be appropriate and a one-off fee charged for this, after which there is an annual fee. Supervision activity varies but includes contact with the Deputy and others, monitoring annual reports, visits from Court of Protection Visitors, and responding to concerns.

Attorneys in England and Scotland:

There is no requirement within the legislation or the regulations for welfare and/or financial attorneys/LPAs to be supported by anything other than the provision of information. Local authorities in Scotland are required to provide information to welfare attorneys on request.

Attorneys have the same duty to apply the principles as lay guardians/deputies with many of the same responsibilities and they may have been granted considerable decision-making powers. Unlike deputies and guardians, lay attorneys have the additional challenge of determining when the person has lost capacity sufficiently to start using the powers granted to them, unless specific conditions have been identified in the power of attorney document. They face the same tough decisions as court appointed deputies or guardians.

Protective measures

Both Acts contain safeguards to investigate complaints regarding the potential abuse of individuals by a guardian, deputy or attorney and, if upheld, to apply for a court order to remove or reduce powers, or seek directions, and, additionally, in the case of attorneys in Scotland, to put supervision in place. Attorneys, guardians or deputies can also seek directions if the individual is refusing to comply and is putting themselves at high risk, or if there are difficulties which cannot be resolved in any other way.

Other support and information for lay proxies

Codes of practice and accompanying guidance have been produced by the Department of Health for England and Wales (the Code of Practice can be downloaded or hard copy purchased for £15). The OPG has a Freephone helpline. In Scotland the codes of practice and guidance are issued by the Scottish Government and made available on request, without charge. Associated guidelines have been produced by the Public Guardian and the Mental Welfare Commission (MWC). Both the OPG and MWC have helplines, the former dealing with financial matters and the latter dealing with welfare matters under AWI and the Mental Health (Care and Treatment) (Scotland) Act 2003.

Specialist voluntary organisations have also produced guides for family members, partners and friends about the incapacity legislation. Carer education courses and one day workshops on AWI and other money and legal matters are held by Alzheimer Scotland and other charities such as VOCAL (Voice of Carers Across Lothian).

3 Key findings

This study found no significant differences between the experiences and needs expressed by lay proxies acting under the AWI or MCA.

1. Most carers reported that, at the time of diagnosis, no-one explained what it would mean for the future and no advice was given about legal issues; no-one spoke to the person diagnosed about the benefits of advance care planning and of appointing an attorney.
2. Some carers were faced with the more complicated and expensive option of applying for a guardianship order because the diagnosis was left too late for the person to appoint an attorney.
3. Most lay proxies were not aware of the codes of practice or related information and did not know about the principles they are required to follow. Many were unsure of what powers they had been granted and did not know that there were limits to the decisions they were able to make.

4. Carers said that, on a day-to-day basis, they did not always know how to judge whether the person had capacity when faced by them insisting on doing something risky. This was a cause of considerable anxiety and conflict.
5. Carers often had to battle to have their powers recognised by banks and building societies, insurance companies, doctors, nurses, social workers and care home staff.
6. Many carers said they did not find making a significant decision difficult, but expressed difficulties in making decisions in the context of:
 - managing relationships e.g. coping with conflict with other family members, professionals or the person themselves;
 - convincing health and social work professionals that the person lacks capacity e.g. to manage self-care without help, despite 'presenting well' at the time of the visit;
 - managing their own emotions and those of the person with dementia;
 - managing their time;
 - knowing their rights when challenged or when choice and standard of service was poor.
7. Carers felt that, in a crisis situation, the need to apply for guardianship was sometimes thrust upon them by professionals, with little chance to consider care options.
8. Carers with financial guardianship or deputyship powers reported mixed experiences of support from the OPG.
9. Welfare guardians and deputies generally found supervision systems were unsatisfactory, being unable to access support when needed. In Scotland research carried out by the Mental Welfare Commission confirmed that many local authorities are not complying with their supervisory duties under AWI, due to lack of resources.
10. Welfare attorneys generally did not know where to go for help when they were faced with challenging situations and were reluctant to approach the local authority or the OPG in case they were judged as 'failing'.
11. Carers expressed an overwhelming sense of isolation in carrying out their task and many said that they had no-one to speak with about the difficulties they face in relation to being a proxy decision-maker.
12. The few carers who had been offered self-directed support with individual budgets were pleased this had worked well.
13. Carers who had attended training and information days on legal and financial issues had found these very helpful.
14. **All but a few carers in the study said they would have attended local training sessions either before or at the time of taking on powers had they been offered. They also wanted an expert professional to consult at times of difficulty and an ongoing peer support network.**
15. Professionals who participated in roundtable discussions identified with the issues raised by carers and said they resonated with their own experience.

4 Key recommendations

Whilst the recommendations below are directed primarily to the Scottish Government and other agencies with duties under AWI, they may also be worthy of consideration by bodies with duties under MCA for England and Wales.

Policy

1. Scottish Government and Westminster Government to recognise the unique responsibilities of lay proxies and strengthen support and protection for the person with incapacity by introducing a national, low cost, easily accessible education programme for proxies or potential proxies. In recent discussions with stakeholder representatives it has been suggested that a **national standard course could be devised and delivered through local colleges in collaboration with specialist voluntary organisations.**

The United Nations (UN) acknowledges that providing appropriate decision-making support in accordance with the Convention on the Rights of Persons with Disabilities will require effort and financial investment, and suggests this might involve a redistribution of some of the existing resources currently used for substitute decision-making. The UK government signed the Convention in 2010 but the full implications of this have yet to be realised in relation to our capacity laws.

The state has a duty of care in relation to:

- ensuring observance of the human rights of the person with impaired capacity;
 - supporting the authority of the person appointed under AWI or MCA to use their powers appropriately and have their status recognised;
 - avoiding or reducing potential crisis situations which are costly to the state and to individuals.
2. Clarify the concept of 'deprivation of liberty' in law and provide a more detailed guide to good practice than currently exists on what it is lawful for attorneys or guardians to do in relation to deprivation of liberty and restriction of freedom.
 3. Revise the MCA and AWI Codes of Practice to clarify best practice and compliance with the UN Convention in relation to:
 - supported decision-making
 - weighing up the significance of wishes expressed by the person now and in the past, when these are very different
 - dealing with conflicts within the family and/or professionals
 - the role of supervision for private guardians/deputies
 - conflict of interests and undue influence.
 4. Newly registered attorneys, guardians and deputies to receive a copy of the appropriate code of practice from the OPG, with costs met from the fee.
 5. The Scottish Government to review the role and effectiveness of supervision and support for private guardians in consultation with guardians and key stakeholders, including specialist voluntary organisations in this field.
 6. The Scottish Government to consider proposals for a simplified form of guardianship where powers needed are limited e.g. to access Self Directed Support.

Practice

1. Early diagnosis and the provision of timely information to be given about advance care planning, powers of attorney and advance directives to become best practice (recognising that this is already a priority within national dementia strategies in Scotland, England and Wales).
2. Training for all health and social work staff acting under AWI or MCA to address skills and knowledge deficits in relation to: knowledge of incapacity law and its principles; capacity assessment; supported decision-making; understanding the status of lay proxies and their support needs.
3. Education and awareness training for care home companies and managers to have an understanding of how the incapacity laws may apply to their residents, and to have protocols for staff where a resident has a lay proxy to make decisions on his or her behalf. In Scotland, the Mental Welfare Commission has produced information and guidance focusing on issues relating to welfare guardianship and welfare powers of attorney in care home and other registered care settings.¹
4. Financial institutions to provide equal access and the same quality of service to lay proxies with financial powers as for any other customer.
5. Solicitors to provide accurate and full information about options available under the incapacity law; to explain responsibilities and duties and operate best practice in recommending only those powers proportionate to the circumstances.

5 About this project

This project built on earlier work in Scotland² to identify issues facing family members, partners and friends who have been appointed as guardians or attorneys under the Adults with Incapacity (Scotland) Act 2000 (AWI); and considered potential responses to meeting their information, support and training needs. As a comparator, the study included a small number of personal interviews and two discussion groups with lay proxies in England, and a roundtable meeting in London with professionals from across the relevant disciplines.

Although there are big differences in provisions and procedures under the two Acts the intentions are the same and these are reflected in the principles embedded in the laws of both countries. Knowledge and understanding of the principles was a prime focus for discussion with lay proxies who took part in the study. The perceptions of agencies with statutory duties under the Acts and of those professionals operating under the provisions of these Acts were also explored in roundtable discussions held in Scotland and England.

The mental capacity laws of several other European countries, as well as Australia, Canada and the US, share a common set of values and principles. The Netherlands and Germany were identified as having systems of support for lay guardians which were worthy of closer attention. Interviews and discussion groups were held with proxies who were recipients of training and support in both jurisdictions. Roundtable discussions were also held with professionals from across the disciplines in both countries.

There has been considerable research interest in the operation of incapacity legislation internationally over the past five years and of significance to this study, a growing awareness of the training and support needs of the increasing number of family members who become

proxy decision-makers for older relatives, dementia being highlighted as the main reason for doing so. This study has identified several initiatives which address these needs (see section 8).

About carers who took part in this project

Most of the 100 carers who volunteered to participate in this study were family members in the mid 30s to mid 80s age range. There were almost equal numbers of male and female carers who took part in either personal interviews or small discussion groups in Scotland and England. Carers who took part were self-selected. There was a great deal in common between their experiences, the challenges they met and the satisfaction they felt they got from their role as attorneys/guardians or deputies. There was also close agreement on the sort of assistance they would have liked.

The study also included 10 interviews and 4 discussion groups with volunteer guardians and family members who were attorneys or guardians in the Netherlands and Germany. Whilst there are differences in the laws to protect people with impaired capacity, the principles for proxy decision-makers to follow are very similar. Family member guardians and attorneys in these countries who participated expressed satisfaction with both the peer and professional supports provided by the local guardianship network.

Questions explored with lay proxies

The following topics provided the framework for semi-structured discussions and interviews with lay proxies:

- Knowledge of dementia and experiences around diagnosis
- Information given about legal provisions for decision-making
- Involvement of the person with dementia in disclosure of diagnosis
- Knowledge, understanding and application of principles
- Experiences of making welfare, health and financial decisions – what helped and what hindered
- Making difficult decisions or dealing with conflicts
- Where did you turn to for help?

6 Issues emerging from the experiences of carers

Dementia, diagnosis, information and support

Whilst some carers experienced good practice in terms of diagnosis and post diagnosis support and information, the majority reported a lack of timely diagnosis and an explanation of the impact of dementia on the person's mental capacity to make their own decisions. The diagnosis often came too late for the person to appoint an attorney. Carers felt this denied the right of the person they cared for to be properly involved in decisions about their future care.

“Find out all you can about the diagnosis as soon as possible and how it affects the person's mind – it came as a shock to me and too late to do things in a way which would have made it better for mum and easier for me. If only the doctor had explained it was more than just her memory going – if only I'd been told what to prepare for”. Guardian, Scotland

About being an attorney or guardian/deputy

The following issues reflect the general experiences of lay proxies:

- Solicitors did not provide adequate information about the responsibilities of guardians/attorneys. It involved far more work (especially for guardians) than they had anticipated.
- A general lack of knowledge of key principles, especially by attorneys.
- Some welfare guardians said that they had been more or less coerced into becoming guardians by social workers and it was not explained to them properly why this was necessary and what was involved.
- Support was not available from professionals when faced with conflicts or difficulties. Welfare guardians had an expectation of having access to their supervisor, which was not matched by that of local authorities. Deputies in England also expressed difficulties around supervision and the fees incurred.
- Lack of recognition of the status and powers of lay proxies by professionals was not uncommon. Medical decision-making was an important area for a number of guardians and attorneys and they had been distressed when they came up against doctors and nurses who failed to understand their rights as substitute decision-maker, even failing to consult on end of life/palliative care issues.
- Proxies for people with advanced dementia said that it was very difficult to continue to involve the person in making decisions, especially where the person had lost the ability to communicate verbally. An application for guardianship was often a last resort, granted when the person had severe dementia and communication was already extremely limited.
- Those proxies in paid employment were the ones who most often referred to using the internet for information about dementia and the law. They reported feeling they knew more than many health or social care professionals about the law and this could create tensions.
- Many carers expressed feelings of isolation and stress arising from caring responsibilities – frequently the proxy was the person's only living relative or sole carer.
- Lack of formal support structures for attorneys; not knowing where to turn for help.

Barriers to making best interest decisions

Lay proxies identified the following issues as hindering them from making what they felt would have been the right decisions for the person i.e. the decision which would have offered most benefit.

- **Poor choice and inadequate services**

The most common and most distressing situation described was where carers were very unhappy about the quality of care or service the person with dementia received. Despite their powers, lay proxies felt helpless to do anything to improve matters in the face of opposition from the local authority or service. One person said that they were told by a care home agency that:

“your power of attorney is worthless in relation to our company’s policy”. Attorney, England

Another carer recently reported that she had many different support workers come into her home each week and had spelt out the need for a small core staff team to care for her husband who became very anxious with strangers.

“My power of attorney was worth nothing. I kept reporting to social work but they did not intervene. I was exhausted explaining everything my husband needed to each new carer who visited, and he was distressed by strangers coming in every day”. Attorney, Scotland

- **Lack of compliance with statutory supervision**

“I don’t know who my supervisor is and I have not had a visit for two years. I tried to contact social services to find out but gave up in the end but things were getting so difficult with the family and I really needed some advice”. Carer, Scotland

Some carers in the study said they found the initial visit helpful but could not remember their supervisor mentioning the principles and how they might use them to make decisions. Supervision provides a potentially very helpful source of support and advice. A frequently mentioned reason for applying for welfare guardianship was to have the authority to protect the person from decisions by public authorities or other agencies, which might not be in the best interests of the individual.

“I agreed to my mum going to a temporary placement until one close to home became available. I kept waiting and was told that after 18 months it might be too disruptive to move her and anyway local beds were needed for hospital discharge. But mum was being deprived of seeing the family and me very often because the home was too far away to reach easily by public transport. Eventually, with advice from Alzheimer Scotland about my rights as an attorney, I found a good place in a care home near by and moved her myself. She has settled very nicely and is pleased to see her grandchildren and daughters again – someone goes nearly every day”. Attorney, Scotland

Difficult decisions

Carers were asked what decisions they had found difficult to make and why. A common response was that it was not the decision itself that was hard, often it was very clear what needed to be done. What was difficult was dealing with other family members or professionals who had a different view, and this was stressful. Most respondents highlighted stress associated with assessing the person’s capacity to understand and make risky decisions when they clearly lacked insight into the dangers. Carers also identified difficulties in dealing with emotions, especially around end of life decisions. In summary, carers expressed difficulties in making decisions in the context of:

- managing their emotions
- managing their time
- managing their family relationships
- dealing with conflicts with professionals
- dealing with financial institutions that don’t recognise their powers
- knowing their rights – especially where there is poor choice of services
- understanding their rights under AWI and under other health and community care legislation in relation to having the right to choose, not being the same as having a choice.

The majority of carers who participated in the study in the UK expressed an overwhelming sense of isolation in carrying out their task. They said they had volunteered to take part because they needed to speak about the problems they faced; they had not spoken to anyone else about the issues arising from being an attorney/guardian/deputy. Those who had sought help and advice had turned to friends and/or turned to websites for information from the OPG or from Alzheimer Scotland or the Alzheimer's Society.

- **Lack of recognition by financial institutions**

Lay proxies with financial powers experienced frustrating problems with accessing the funds of the person because banks were reluctant to recognise their authority or demanded ID for the person with dementia which they no longer possessed such as a passport or driving licence. This often led to delays whereby the carer was out of pocket, having to pay bills from their own funds until the matter was sorted out.

“The bank would not accept my power of attorney certificate at first – they said I had to bring my mother in with me with her driving licence, passport and utility bill – crazy – I said she had none of these as she was wheelchair bound and living in a care home and the reason I am her attorney is because she has dementia. I insisted they ring their legal department or the OPG to check the register. Eventually they believed me”.

This issue was confirmed by the OPG in a roundtable meeting:

“Financial institutions are consistently bad at not accepting the OPG’s seal”.

People with dementia who are unable to manage their finances should not be denied access to their own money and barriers to this may be in breach of equality laws.

What carers in Scotland and England said would help

- **Early diagnosis and post diagnosis support and information**

Early diagnosis and having the implications of the diagnosis explained sensitively to the person diagnosed so that they can come to terms with it and consider appointing someone they trust as their attorney was viewed as the key to helping to deal with everything which follows. Carers who experienced good practice said that it made decision-making at a later stage very much easier.

“ My mother was given an early diagnosis and this was explained to both of us by the consultant – it helped us to prepare. Mum appointed me as her attorney and this helped a lot with making decisions later”. Attorney, Scotland

- **Healthcare professionals with a good understanding of dementia and incapacity laws** in relation to the rights of lay proxies and where to signpost for advice.

“ The Consultant understood my powers and explained to the care home that they had to go to me for all decisions about her medication”. Attorney, Netherlands

- **Knowing the principles and how to use them** - carers in the study said this information would have helped support their negotiations with social workers and family members when faced with different views about what should happen; and that a practical guide to implementing the principles and how to weigh up options would be very helpful.

- **Having access to peer support** - carers in Scotland and England treated the discussion groups as support groups and expressed a desire for ongoing support networks to be established, preferably by voluntary organisations. They would have attended introductory training sessions if they had been available.

“ I felt so alone in this role – isolated – I’ve never spoken to anyone about it – I’ve no close family and you don’t want to burden friends. It would be good to have a peer group network to share experiences with”. Guardian, Scotland

- **Having access to a short introductory training course** at an early stage of their ‘career’ as lay proxies so they would have a better understanding of their rights and responsibilities; how to relate to external agencies and dealing with disagreements. Proxies with financial powers said they would like the Office of the Public Guardian to provide training on financial management and reporting issues before an appointment was made so they would know what was involved.
- **Access to information about rights, entitlements, SDS and standards of care.** Some carers were aware of Self Directed Support and were happy with arrangements. Others did not know about options available or what they could ask for.

“I had no idea I could ask the OT to visit my mum’s home to make it safer for her – now I don’t have to worry about the gas being left on or the water overflowing as they fitted gadgets to turn them off automatically – they also came up with ideas to help her do things for herself more easily”. Attorney, Scotland

“I needed to continue work when my husband was diagnosed with early onset dementia and had to give up his job. Social workers were great in getting me an individual budget to pay for 26 hours a week support. This meant he could have a support worker take him out to do the things he enjoyed – not be stuck in a day centre”. Deputy, England

7 Issues emerging from roundtable discussions

There was a consensus amongst professionals on the issues raised by lay proxies and a high level of empathy and interest in the need to find solutions.

- Professionals felt that carers of people with dementia, whether or not they have been granted legal powers, needed support and training around decision-making processes.
- When presented with issues raised by lay proxies, professionals did not disagree. The Mental Welfare Commission for Scotland, which has a free telephone advice line, reported a resonance between the findings of this study and those of the MWC. A third of all calls to the helpline relate to AWI. Misunderstandings about the role of the attorney and a lack of understanding about capacity have been exemplified in two recent investigation reports by the MWC. In the case of Mrs I³, who had severe dementia, it was not only the siblings with welfare power of attorney who believed that they had to adhere to the wishes of their mother not to be moved to a care home under any circumstances, but the professionals too, who allowed Mrs I to deteriorate to such an extent that she was eventually compulsorily detained in a hospital.
- The rapid rise in the number of attorneys reflects the needs of our ageing population, and monitoring practice in any meaningful way was not felt to be possible. However,

the number of complaints and investigations is increasing, with the potential for abuse and neglect by lay proxies.

- It was suggested that, since guardians and attorneys are required to comply with the principles in decision-making and the duties set out in the code of practice, they should be automatically provided with a copy at the point of registration, with costs covered by the fee.
- There was a consensus about the importance of early diagnosis, and the right of individuals to be informed about their diagnosis, with the offer of support and information. Experience across Europe was variable, with issues arising from lack of dementia specialists and reluctance to disclose diagnosis.
- It is important to note that earlier in 2012, the Scottish Government made a commitment to providing a minimum of one year's post diagnostic support, to include the provision of financial and legal information. This policy is to be included in the second National Dementia Strategy to be introduced in 2013. Post diagnostic support is also a priority within the Dementia Strategy for England.
- The Scottish Human Rights Commission in Scotland drew attention to the implications of the United Nations Convention on the Rights of Persons with Disabilities⁴. Article 12 relates to physical and mental disability: the state must take reasonable steps to support capacity and provide the right to regular reviews where capacity is an issue. The need for best practice guidance on supported decision-making was emphasised; and that practitioners need to improve practice in relation to care planning with people diagnosed with dementia and their carer/s.
- The concept of 'deprivation of liberty' embedded in the European Convention on Human Rights lacks a clear definition and this has become an issue of concern across Europe. Under AWI, there is a question of how far the law allows welfare attorneys to intervene when the person resists or objects, for example, in relation to medical treatment or the refusal of services. The Scottish Law Commission (SLC) is reviewing AWI with a focus on the issue of deprivation of liberty and limits to freedom, including what an attorney or guardian is able to do within the law. The SLC will be publishing a discussion paper for consultation on its recommendations in summer 2012. Alzheimer Europe currently has a working group considering ethical issues around deprivation of liberty and restrictions on freedom with a view to publishing a good practice guide in 2012/13.
- Attention was drawn to the findings of recent studies⁵ which served to demonstrate how the human rights of individuals can be unwittingly undermined by professionals due to a limited approach to the concept of autonomy and lack of understanding of how an assessed person's capacity can be affected by their emotional state e.g. high levels of anxiety and stress when faced with major life changing situations, and non-compliance with the principles of the incapacity laws by professionals.
- Poor compliance by local authorities with their duty to provide supervision to all welfare guardians. The Mental Welfare Commission survey⁶ found that 53% of local authorities who responded said that they did not have the resources to meet their duties in all cases and only 17% said they did so. Supervision is potentially a very useful system of support for lay guardians, but many local authorities are giving priority to cases where there are perceived risks to the autonomy of the individual, mainly young people with a learning disability, and often consider guardianship for someone with dementia who is in a care home as 'unnecessary'. This has given the impetus for discussions around

whether the statutory minimum number of visits per year should be reduced further. The MWC, with the Social Work Inspection Agency, has produced a Practice Guide to Supervising and Supporting Welfare Guardians⁷ which has revitalised training for social workers carrying out supervisory duties in some local authorities.

- The lack of recognition for the authority of financial powers of attorney /guardians/ deputies by some financial institutions was commonly experienced and confirmed by the OPG in Scotland. There is agreement that the problems faced by financial proxies amounts to discrimination and should be tackled as such. The Public Guardian in England is working with the British Banking Association to increase compliance and awareness of LPA/Deputyship arrangements.
- Poor compliance with the principles by some legal professionals i.e. recommending an application for plenary guardianship powers for an indefinite period, regardless of individual need. This has been identified as an issue in Scotland by the Mental Welfare Commission and local authority Mental Health Officers. Whilst powers granted for an indefinite period may be appropriate for someone with a progressive dementia, plenary powers, which include control over social contacts, may not be appropriate e.g. sometimes being used inappropriately to exclude other family members from visiting the person. It is also the case that people with certain forms of dementia may recover sufficient capacity to no longer need guardianship e.g. someone with Korsakoff's dementia.
- The personalisation of support and the provisions within the Self Directed Support (Scotland) Bill currently going through the Scottish Parliament have the potential to enable lay proxies to ensure the person receives the assistance best suited to the person's needs and wishes. However, the requirement to be a legally appointed proxy in order to access SDS for a person with incapacity will restrict its use and the benefits to be gained by the many people with dementia who do not have a proxy decision-maker. This may have the impact of increasing the number of private guardianship orders with the demands on scarce resources that this would impose. Alzheimer Scotland regards the requirement for welfare guardianship for this purpose alone as disproportionate in many cases. Proposals arising from both the OPG and MWC to review AWI guardianship provisions and consider models for graduated guardianship would address this issue.

8 Support systems elsewhere - learning from experience

An updated literature review and information obtained through contacts within Alzheimer Europe and the International Guardianship Network suggests that there is a growing awareness of the increase in number of lay guardians for people with dementia and their need for information, education and ongoing support. This may reflect a realisation that our ageing population will impact on the use of provisions under incapacity laws and the need for policy and practice to comply with the United Nations Convention on the Rights of Persons with Disabilities. The UK government signed the Convention in 2010 but the full implications of this have yet to be realised in relation to our capacity laws.

In most jurisdictions, family members or friends are recognised by judges as being likely to make the best guardians because they are very familiar with the person's needs and wishes and have a strong commitment to ensuring their wellbeing. However, a family judge in the Netherlands observed that "a willingness to 'do your best' is not the same as being well informed to do your best".

Initiatives to support lay proxies

Initiatives have been identified in several jurisdictions in the United States, Australia and Europe and these are outlined below. However, only in a few jurisdictions is there an established systematic approach to the provision of training and support for lay guardians and, where such initiatives exist, they tend to be geared towards the selection, training and support of court appointed volunteer guardians for vulnerable individuals who have no family member or friend to act for them and are not generally accessible to privately appointed attorneys.

In 2008, a Learning Partnership and Knowledge Exchange on Adult Volunteer Guardianship, funded by the EU, was established with participants from Germany, Austria, the Netherlands, Switzerland, Italy and Japan. The project looked at models for the education of volunteer guardians in Europe and raised questions about training and support for family member guardians.⁸

This study looked at the models for the training and support of volunteer guardians in the Netherlands and Germany because of the statutory, systematic nature of the provision and to see what, if anything, might be adapted and developed to meet the needs of family members, partners and friends who become guardians or attorneys in the UK.

Initiatives in Europe

Education model of the Mentorschap Network Nederland

The model described below exemplifies the most comprehensive and systematic approach to supporting volunteer guardians that the study has identified. The scheme was designed to support legislation which enables the court appointment of volunteers to act as guardians. Certain strands of the support model are open to family member guardians and attorneys. Whilst the model is not entirely appropriate to meeting the needs of family members, there are strands which could be adapted. There is a demand from family members appointed as guardians or attorneys for training and support and the Network is currently considering how to extend its support and training to them.

The Network operates through a regional structure of foundations with a central office at its hub. Regional offices employ a coordinator who recruits, selects and trains potential volunteers for appointment by the court, and provides ongoing support for the duration of the guardianship. The central office ensures a quality system is in place and standards of practice are independently audited. The system was initially fully funded by the government with a fee charged to clients (the person for whom a guardian is appointed) but there is a growing drive for local authorities to resource these schemes.

The Mentorship system of training and support has developed a philosophy of learning which includes peer group learning, with input to the introductory and topic based sessions from professional experts. The model has four strands:

1. Introductory Course – six topic sessions, including:
 - legal issues
 - ethical decision-making
 - types of illness and incapacity e.g. dementia
 - communications
 - negotiations, co-operation
 - care sector.

2. Personal coaching (provided by the coordinator).
3. Theme based workshops - held two or three times a year on specialist topics.
4. Intervision – this is case based learning with a small peer group of lay guardians.

Germany - Betreuungsverein system (Berlin)

The Betreuungsverein system is also designed to recruit, select, train and support court appointed guardians. Local voluntary organisations are commissioned by the local authority to establish a dedicated service to identify and match up volunteers who become court appointed guardians to individuals who have no family or friends to act for them. Induction training is provided to newly recruited volunteer guardians. The particular strength of the service observed in Treptow-Kopenick in Berlin is the provision of one-to-one support and topic-based training sessions which is open to family guardians. The service is staffed by an interdisciplinary team of experts who are also appointed as guardians in complex cases. The service is subject to independent audit to ensure standards of practice are met.

Austria

Austria was part of the learning exchange referred to above. In the report of the workshop presentation from Austria, pertinent questions were raised on the question of how learning can best be developed around ethical decision-making and taking on the responsibilities of guardians for family members and friends. Evening classes which consisted of two three hour sessions covered the legal foundation for guardianship, practical advice and a focus on ethical issues. This was not a country-wide system. However, a new educational model and curriculum is currently being developed and introduced during 2012. It will be useful to follow up this development.

Initiatives in the United States

In some US states, there is compulsory training and accreditation for professional guardians, and family member appointees are encouraged to participate. The well established National Guardianship Association aims to promote standards of excellence in guardianship practice through its Center for Guardianship Certification. NGA has produced comprehensive learning materials, including a module on making ethical decisions. Resources are available on the NGA website⁹ and can be accessed by lay proxies as well as professionals. There is a membership fee and a fee for registering for each learning module.

A report from the National Center for State Courts, Center for Elders and the Courts¹⁰ Adult Guardianship Court Data recognised the support needs of lay guardians and asked questions about the training provisions in its on-line survey, which received responses from 36 states.

A relevant finding from this study was that 68% of respondents indicated that about 72% of guardianship cases were served by family or friends. The report notes that the responsibility of guardianship can be overwhelming, especially in cases where training is not available or inadequate.

'The family guardian shoulders a heavy responsibility. Family guardians must perform a complicated array of tasks that place them in regular contact with a range of health, care and financial agencies on behalf of the person. Of particular concern is the ability of the guardian to navigate through the convoluted systems. Very often the guardian receives little or no help, thus adding to their emotional and financial burdens.'

Results from the survey suggest that statewide training programmes are rare but do exist. For example, Florida requires a minimum of 8 hours' instruction and training for family guardians. Several respondents noted that their states were working on implementing training programmes (e.g. Oregon, North Dakota, Massachusetts).

Washington

A Report of the Guardianship Task Force to the Washington State Bar Association Elder Law Section Executive Committee stated:

'A guardian's work can be extremely demanding and difficult and often goes unacknowledged Incapacitated persons are vulnerable. Guardians who do their jobs well can significantly reduce this vulnerability and enhance quality of life. Guardians who fail to discharge their responsibilities can cause serious harm.'

'It is not uncommon for lay guardians to sometimes feel lost in the guardianship process. Guardians have a broad range of responsibilities that are set forth in complicated statutes. Without training requirement for lay guardians there is no assurance that lay guardians know or understand their responsibilities.'

The summary of findings in this Washington State report are relevant to this report.

- Lay guardians are typically family members or friends who serve without pay.
- Training for lay guardians is not consistently required or readily available.
- Training should be required for lay guardians. Although lay guardians assume fiduciary duties and other legal responsibilities for incapacitated persons, Washington does not require lay guardians to receive training.
- **Washington should have a minimum statewide training requirement for lay guardians and provide low-cost, easily accessible training resources.**
[author's emphasis]

Guardianship Assistance Program New York

The Guardianship Assistance Program offers practical advice and training for lay guardians under Article 81 of New York State Mental Hygiene Law. It can help with practical issues but also with 'making a plan for the person that allows as much independence as possible' and 'locating resources to help you care for the person'.

Initiatives in Australia

New South Wales – Private Guardian Support Unit

The Public Guardian for New South Wales has a Private Guardian Support Unit which provides free and confidential services to assist legally appointed guardians in their role. The Public Guardian has also issued a 'Capacity Toolkit – Information for government, community workers, professionals and families and carers in New South Wales'¹¹.

Victoria

The Law Reform Commission, Guardianship: final report ¹²(18 April 2012), recommended the provision of on-going publicly funded and comprehensive education programmes about key aspects of the guardianship system – widely available and targeted to meet the needs of individuals, organisations and the general community.

Key learning points from international initiatives

- State-wide education programmes for lay guardians are at an early stage of development and have been introduced in response to the need to ensure compliance with reforms to capacity laws and international human rights conventions, also in recognition of the heavy responsibilities that family members take on when they become legally appointed proxies. There is an awareness that support and training for the proxy may help to ensure decisions are made in the best interests of the person and reduce the potential for abuse or neglect.
- Where courses are open to family members and friends, they are appreciated and reported to be effective in meeting their information and emotional support needs. A number of states and countries across Europe (most notably the Netherlands and Austria) are recognising the need for training programmes to be designed and targeted specifically for family members, partners and friends who become legally appointed proxies and are actively working to put these in place.
- The models of training identified have a similar participatory/peer learning philosophy, with core topics covering: legal issues, decision-making processes and applying the principles / dealing with ethical issues, capacity issues, dementia/other conditions, negotiation/co-operation, understanding health, social care and welfare benefits systems.
- Themed workshops every few months were well attended by lay guardians and provided ongoing peer support and access to expert advice.
- State wide, publically funded guardianship services, such as the Private Guardians Support Unit in New South Wales and the education programme in Victoria, provide easy access to specialist, personal, confidential advice through a 'single door' service which deal with both welfare and financial issues. They also provide out-reach training programmes for the public and proxy decision-makers.

9 Conclusions – the need for action

Demographics

Statistics show that increasing numbers of people are registering powers of attorney as an insurance against future incapacity. On the other side of the equation, more people are being appointed as attorneys by older relatives and friends. Statistics held by the Office of the Public Guardian Scotland, show that 50% - 60% of welfare guardians are family members caring for someone with dementia. One in four people who live to be over 80 is likely to develop dementia and may need a proxy decision-maker to manage their finances and make health and social care decisions on their behalf. It is therefore in everyone's interests that the information, support and training needs of lay proxies should be formally recognised and met.

Impact on families

The incapacity law reforms were introduced to empower people with dementia and others with mental impairment to be regarded as full citizens within the community and not disadvantaged in any way. Family members, partners and friends have the complex task of moving between supporting the person to make their own decisions, to making decisions together and when necessary, using their powers, to act as substitute decision-makers. They

demand very little for themselves, yet there are high expectations of how they should perform. Without the agreement of family members to take on the duties of a proxy decision-maker, there would be a huge burden on the state to put other protective measures in place.

Impact of new policies

The implementation of the Scottish Government's personalisation agenda is supported by two key policies, both of which can be predicted to impact on the number of powers of attorney being registered and the number of applications for guardianship.

First, the Scottish Government's commitment to include a guaranteed minimum of a year's support following diagnosis in the forthcoming revised National Dementia Strategy. This will ensure that the person diagnosed, whilst they are still able, will have the information and opportunity to appoint someone they trust as their attorney. This landmark policy is widely welcomed. It is anticipated that it will give rise to an increase in the number of appointments of welfare and financial attorneys and, as a consequence, there may be a reduction in the number of private guardianship applications. If this happens, the shift will also represent savings for individuals and for public resources (especially those associated with applications for welfare guardianship in particular – court costs, assessments by two medical practitioners and mental welfare officer, supervision, etc).

Secondly, the forthcoming introduction of Self Directed Support legislation which requires the authorisation of a legally appointed proxy in order to access individual budgets for a person who lacks capacity. Carers who have not been granted powers of attorney will have to apply for welfare guardianship in order to access funds. A simplified system of access with appropriate safeguards will need to be introduced if people with dementia who lack capacity and those who support them are not to be disadvantaged.

Human Rights

There has been considerable progress over the past decade to recognise the human rights of people with dementia and their carers.¹³ Many thousands of carers strive every day to ensure the person they care for receives the best possible support. AWI makes provisions for them to have the authority to act and make decisions for the person who can no longer do so for themselves. As the experiences of lay proxies in this study illustrate, they face a great many challenges in doing so, but with very little information or education about how to perform their duties.

The recommendations for policy and practice are set out in section 4 of this report. Central government, local authorities and other agencies with duties under incapacity laws are asked to consider implementing the recommendations within the context of progressing the human rights agenda and in particular, compliance with the United Nation Convention on the Rights of Persons with Disabilities.

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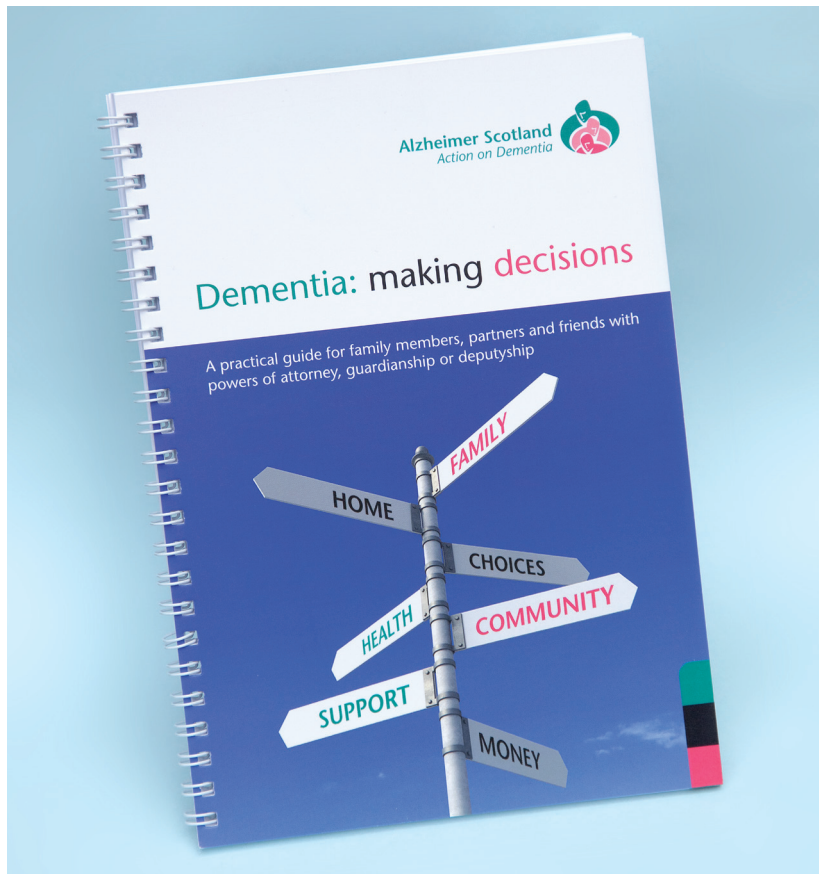
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This practical easy to read guide shows how the principles within the UK incapacity laws can be used to empower the person with dementia and strengthen the authority of the proxy when acting on their behalf. It provides a useful checklist on supported decision-making and signposts to specialist help.

The Guide can be downloaded at the Alzheimer Scotland website at: www.alzscot.org/decisions. In Scotland, hard copies are available free on request singly or in bulk from Alzheimer Scotland e-mail: alzheimerscot@alzscot.org or by telephone to the Dementia Helpline on 0808 808 3000; in England or Wales from the Alzheimer Society UK, Helpline: 0845 300 0336.

"Those who have been appointed as legal proxies under the incapacity laws need to have confidence that they are acting in the best interests of the adult. While the provisions cover all adults who lack capacity, it is those with dementia who form the majority, and so it is extremely helpful to have their particular situation covered in this guidance". Nicola Sturgeon, MSP, Deputy First Minister, Cabinet Secretary for Health, Wellbeing and Cities, at the launch of the Guide, Edinburgh, 2012.

"From my perceptions of having been a consultant psychiatrist, as a medical ethicist and currently as a carer for my mother who has dementia, the guide passes the test on all three fronts and I can highly recommend it". Tony Hope, Uehiro Fellow, Oxford Uehiro Centre for Practical Ethics and Emeritus Fellow at St Cross College Oxford at the launch of the Guide, London, 2012.

Dementia: autonomy and decision-making: putting principles into practice.

This project has enabled research into the support needs of carers of people with dementia who have the additional burden of becoming substitute decision-makers for the person they care for, appointed under the following laws in Scotland, England and Wales.

Scotland: Adults with Incapacity (Scotland) Act 2000

England and Wales: Mental Capacity Act 2005

These reforms were introduced to protect the rights of individuals who lack capacity to make some or all decisions for themselves and to support their families and others with powers of attorney, guardianship or deputyship in managing and safeguarding the person's health care, welfare and finances.

Whilst there are some important differences between these laws across the UK and how they are implemented, the principles are based on the same set of values and principles set out in the Human Rights Act 1998.

Unfortunately, the rights of people with dementia are not always well understood and their proxy decision-makers often face challenges. This report highlights issues voiced by carers and sets out key recommendations for consideration by agencies and individual professionals with duties under the capacity laws.

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Alzheimer Scotland is committed to improving the lives and opportunities of people with dementia, their families, partners and others providing support and care. We do this by campaigning for the rights of people with dementia and their families, partners and friends. We provide specialist dementia care services across Scotland and raise funds to provide our 24hr Freephone Dementia Helpline (0808 808 3000), our networks of Dementia Advisors and Dementia Nurse Specialists, and our Dementia Research Centre.

