



**Alzheimer Scotland**  
*Action on Dementia*

# Dementia: autonomy and decision-making

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# Adults with Incapacity (Scotland) Act 2000

Promote and protect the rights of people with a mental disorder who lack capacity.

Capacity assessment is decision specific

Provisions: appointment of welfare and financial attorneys and guardians



This project is funded by the Nuffield Foundation to address the question:

***How can support be provided to lay proxies (family members, non-professionals) to ensure the rights of the person with dementia for whom they act are respected?***



# The law and decision-making

- In Scottish law, proxies must act implement a set of principles which reflect the rights of people who lack capacity to make some or all decisions for themselves.

# Principles

- The Act gives powers only to take those actions or decisions which the person cannot take for him/herself
- Must benefit the person
- Must take account of person's past and present wishes and feelings – must assist the person to communicate these by all possible means



# Principles

- Must restrict the person's freedom as little as possible to achieve the desired benefit
- Take account of views of relevant others as far as practical
- Encourage the adult to use existing skills and develop new skills



- Many European countries, Australia, Canada and the US share a common set of principles to support and protect adults with mental incapacity (not always embedded in law).

# Project objectives:

- identify unmet support needs of lay proxies (family members and non-professionals) who often face conflicts and difficulties in making decisions on behalf of the person with dementia;
- identify models of good practice which provide lay proxies with the information, training and support they need to help them uphold the rights of the person with dementia





# Outcomes:

- Develop a good practice guide to support lay proxies.
- Promote models of good practice and disseminate in a variety of ways.
- Influence policy development

# Methodology

This qualitative research includes:

- a literature search;
- series of semi-structured focus groups and individual interviews with attorneys/guardians;
- Seminars with key stakeholder agencies with duties under relevant legislation



# Fieldwork: Scotland, England, Holland and Berlin

- 11 focus groups
- 35 one to one interviews
- 90 individuals in all with either power of attorney or guardianship – welfare and financial powers.
- 4 seminars

# Research Collaborators:

- Scotland: the Public Guardian and Mental Welfare Commission
- England: the Public Guardians for England and Alzheimer's Society
- Holland: Alzheimer Nederland & Prof. Kees Blankman, Family Law
- Germany, Jochen Exler-Konig, Betreuungsverein Treptow-Kopenick



# Key issues explored:

- Experience of having legal powers to make decisions
- Knowledge and understanding of the law and key principles/rules
- Knowledge about rights of person with incapacity

# Key issues explored

- Challenges and dilemmas – making health, welfare, financial decisions
- Recognition of powers by authorities/agencies/professionals
- Understanding of capacity issues

# Emerging Themes:

## Importance of early diagnosis

- Proxies stressed the importance
  - of having early diagnosis, & post diagnosis support - crucial to empowering person with dementia e.g. power of attorney.
  - understanding dementia essential to understanding support needs, rights/decision-making issues.



# Knowing the law - professionals

- medical decision-making was an important area and some proxies found health and social care professionals had no knowledge or understanding of the Act and did not accept/recognise their legal powers without a battle.



# Knowing the law - proxies

- attorneys and guardians interviewed in Scotland were **not** generally aware of their duties under the law – most people were not aware of the code of practice;
- Information not always user friendly



# Proxies felt disempowered

- Unable to improve quality of care/life because services unresponsive to requests; an attorney was told by a care home that *'your power of attorney is worthless in relation to our company's policy'*.



# Family conflicts

- Sons and daughters with poa said that the most difficult decisions were those where they have had to go against the wishes of the spouse (to keep their husband/wife at home at all costs even where their own health was seriously failing);



# Involving the person with dementia

- Cares of 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; knowledge of past wishes and preferences helped



# Knowing the 5 principles/rules

- Proxies in Scotland said that it would have been very helpful to making decision had they known about the 5 principles – it would have helped them in negotiations with social workers and family members;

# What lay proxies would like

- To be better informed about dementia, legal and financial issues early on.
- To know what the law says; what the key principles are and how to use them
- Self-help support groups – share experiences
- Professionals to be aware and trained re. power of attorney and guardianship



# Learning from Holland & Germany

- Both countries have laws which require provision of training and support to volunteer guardians.
- Recently open to family member attorneys and guardians (but not compulsory). One to one support from staff especially valued.



# Training and support

- Both countries have dedicated guardianship networks and state funding for agencies.
- One family member said she would have felt 'completely helpless' without one to one support. Others found sessions on making ethical decisions very valuable.





# Stakeholder Seminars Programme (4)

Aim to gain the perception of professionals on their role and how legislation is working to support proxies and rights of individual; to feedback issues raised by families/volunteer guardians

# Emerging themes

- Importance of early diagnosis in relation to human rights/discrimination and social inclusion is not well understood.
- Inadequate resources for care are a big issue everywhere
- .Learning curve on assessing capacity



# Good practice advice from lay proxies

- Appoint someone your trust to be **your** attorney **now**.
- Be an attorney or guardian – but **know what you are taking on**
- Know the principles
- **Keep asking questions, be assertive, don't give in!!**



# Next steps

- Complete fieldwork and analysis
- Draft Good Practice Guide to making decisions (with involvement of reference group)
- Draft project report – implications for policy and practice
- Launch reports England/Scotland  
May 2011



# Further information

Office of the Public Guardian for Scotland

[www.publicguardian-scotland.uk](http://www.publicguardian-scotland.uk)

Mental Welfare Commission for Scotland

[www.mwc.scot.org.uk](http://www.mwc.scot.org.uk)

Scottish Government

[www.scotland.gsi.gov.uk/justice/](http://www.scotland.gsi.gov.uk/justice/)

Incapacity

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