

Excellence in dementia care

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Going for **Gold**
Meeting the
Dementia Priorities



Human Rights

People with dementia are entitled to the same human rights as everyone else

- Dignity
- Respect for privacy and family life
- Autonomy
- Equality

2008 UN Convention on the Rights of Persons with Disabilities

Non-discrimination, accessibility, inclusion in society and the freedom to make one's own choices are core principles.

“Independence and personal autonomy is not about doing everything on your own, but about having control over your life and the possibility to make decisions and be respected by others.”

Rights and incapacity law

- No one should be disadvantaged due to impact of dementia
- Principles of the Adults with Incapacity Act: good practice guide
 - must benefit the person
 - least restrictive on person's freedom
 - must hear person's past and present wishes
 - involve relevant others
 - maintain skills and encourage new learning



Empowerment

- Health and community care policy focus on putting the service users at the centre
- How does this work for people with dementia? Early diagnosis and support services will help

BUT

- Current funding system for community care is a barrier.

Recognising the Mismatch

Personalisation of care = empowering people to make choices based on own life-style

Government policies should drive this forward

Policy tension:

Current system for block commissioning and funding services > crisis intervention > limited options > generic not specialist dementia care services

Moral imperative to change system

Quality standards agencies found

- Not enough strategic planning for dementia
- Too much variability between councils/HBs
- More training and awareness raising needed
- Low priority for development of services
- Profile of services is **still traditional**
- Concept of individual outcomes based commissioning is not well developed
- Quality of continuing care transferred to private sector from NHS accommodation is worrying
- Good range of individual projects

Personalisation

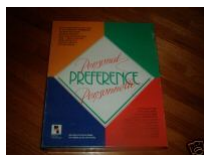
- Services enabling informal supports – family, friends, neighbours,
- Services responsive to flexibility carers need to live their lives and support the person with dementia
- Services which are flexible 24/7
- Funding pot allocated per person to be used creatively to meet individual preferences

Details About



My Life

Personal Preferences



and Routines

Still too many bad stories

- Carer found partially sighted mother sitting in the dark – light bulb had gone
- told '*handyman is off all week*'.
- Reported again and told – '*there's a light in the toilet*'
- Asked to replace light bulb herself and told '*no – health and safety issues*'

And more...

- Carer: Mother is very small – underwear size 18 found in her draw – rarely are her own clothes there – '*it happens week after week – I made a special list of her clothes – named everything – thought she might have at least a little choice – found the list thrown away in the dustbin*'.
- Told he is in nappies because we don't have time to take residents to the toilet.

Misuse of antipsychotic drugs

- Recent research has shows:
- 40% of older people in care homes are prescribed antipsychotic drugs
- 70% don't need them
- Cost to individuals in terms of side effects- increased risk of stroke, premature death, confusion, drowsiness etc incalculable;
- Cost to NHS between £5-8 million a year

Lots of Good Stories

- Complex care packages allowing spouses to stay together at home
- Flexible one to one support
- Dementia friendly design in care homes
- Care homes promoting independence and enhancing lives
- Leadership - sense of pride – happy staff = staff retention

Excellence: understanding

- Psychological impact of diagnosis and loss of control – apathy, anxiety, aggression, depression
 - Recognising ‘person-hood’ and how to help reinforce sense of identity and esteem
 - how to interpret behaviour based on - - in-depth knowledge of the person - their relationships, work, what they loved and hated etc.
- Lots of training resources and expertise available

Working it out - communication

- The opera singer - person with dementia in day care made constant loud noises, would not be distracted by activities offered – checked out for pain, discomfort etc
 - looked into her background and found she had been an opera singer – adjusted activities to match her interests constant ‘singing’ stopped.
- Many similar stories – relating to ‘walking’ /‘wandering’– many hill climbers in Scotland!!

Quality of Care

- Importance of accurate - differential diagnosis – use of appropriate anti-dementia drug treatments along side:
- emotional and practical support and information for the person with dementia and their family
- Personalised services to support QoL
- high quality palliative care

Drivers for excellence

- **Government clinical priority for dementia care and palliative care**
- **Redesign of funding to enable personalisation of services**
- **Dementia Training Action Plan**
- **Dementia specific standards**
- **Designated leaders**

The equation for excellence in dementia care

Human rights awareness + knowledge + skills + policy priority + implementation action plan + resources = excellence

Alzheimer's Priority for EU



Collaboration

- Research networks
- Sharing Good Practice
- Focus on ethical issues within both

**Working together to achieve excellence –
need for local dementia care networks?**



Alzheimer Scotland

Membership organisation:

- Providing community based services
- Information service
- Campaigning and raises awareness
- **Freephone 24hr Dementia Helpline**

0808 808 30025

www.alzscot.org

Reference

- Excellence in Dementia Care – Research into Practice. Edinburgh. Murna Downs and Barbara Bowers. OU Press