






# Making connections

-  What are your experiences of being consulted, for example about your views of a product or service?
-  What are your experiences of being asked for your consent?
-  What helped in these situations?
-  What made them more difficult?
-  What can we learn from our own experiences about supporting people with dementia?

# **Ethical issues in consultation work**

- Consent - ensuring that people are happy to participate**
- Confidentiality & protecting identities**
- Ensuring people do not fear or experience negative effects of expressing their views**
- Addressing issues of abuse/neglect or other unacceptable practice that consultation or involvement work exposes**
- Need for official ethical approval in some instances**
- Involvement of relatives / other supporters**

**adapted from Cantley, Woodhouse & Smith (2005)**

# Consent and people with dementia

Situations in which consent issues commonly arise:

Practice issues:

- Major decisions about care/treatment
- Day to day decisions about care
- Seeking immediate information about views of care





Research

- Consultation exercises
- Other kinds of research

# **Some factors to consider**

**Legal matters e.g. Adults with Incapacity Act in Scotland etc**

**Regarding persons with dementia**

-  uniqueness of individuals**
-  longstanding values & dispositions**
-  preferences regarding ways of making decisions**
-  effects of dementia – fluctuating, global/  
specific, interaction with health and wellbeing**

# **Traditional approaches to consent**

**Valid consent has 3 main elements:**

- the person is competent**
- the person is fully informed**
- consent is given freely and willingly**

**Generally addressed once at the beginning of a process**

**Largely exclusionary to people with dementia**

# **'Inclusionary consent' Jan Dewing (2002, 2007)**

**Need for:**

- individual approach to persons regarding specific decisions**
- account to be taken of individual abilities and needs**
- face to face contact**
- some information about person's life story**
- information about usual levels of wellbeing and illbeing, and how these manifest**
- knowledge of triggers to changes in well- and ill-being**

## **‘Inclusionary consent’ (cont)**

- account to be taken of fluctuations in abilities & wellbeing and approach at good time**
- attention to stories person tells**
- use of indirect methods of enquiring e.g. 3<sup>rd</sup> person approaches**
- use of props, pictures etc to illustrate request**
- continual revisiting & renegotiation of consent**
- transparency & detailed documentation**

**Dewing’s 2007 paper describes in detail an approach to process consent**

# Providing information and using consent forms

Information materials should use:

- simple language
- short sentences
- no jargon, acronyms etc

Use pictures, for example:

- photograph of researcher
- building where work will take place
- illustration of what will happen - group discussion etc

Consent forms should ask specific questions e.g. “Is it okay for Kate to make a video of our talk?”