

# Down syndrome and dementia: challenging methodology to develop a framework for supportive care

## Examples of key practice issues

	Communication method	Eating and drinking	Staff issues	Daily living
<b>Private accommodation</b>	Verbal - deteriorated and became difficult to understand. Stammer increased when worried. Routine self talking.	Frozen ready meals, the same every day. Lack of support with menu planning and nutrition.	Pictorial staff rota used but picture not changed if staff changed their shift.	Attends college, travels independently. Heating turned on high all year. Lonely, bought a toy for companionship.
<b>Intellectual disability group home</b>	Non verbal – pictorial. Appropriate form of pictures to use for communication had to be identified.	Lengthy mealtimes with staff and other tenants. High staff/ resident ratio.	Waking night staff with visible presence. Staff trained in learning disability and dementia.	Reduced then stopped attendance at day centre due to difficulties with travel and noise at the centre.
<b>Nursing home</b>	Non verbal – touch and senses. Built on previous interests in handbags and textures. Likes to hold hands.	Rushed mealtimes, food was removed even if person was unable to feed themselves. Non verbal cues missed.	Staff did not always speak in same language as residents. No awareness of the different reality of a person with dementia.	Did not go outside for over two years. No interaction with other residents.

## Adapting the Methodology

Three case  
study reports  
from different  
accommodation  
settings.

Consent from  
people with  
Down syndrome  
and dementia.

Non verbal  
communication  
including body  
language, touch,  
pictures.

Grounded theory  
as the research  
developed based  
on issues important  
to the participants.

Narrative  
research methods,  
participants chose  
what and how  
to communicate.

Ethnographic  
research in  
participants  
own homes  
over three years.

### Recommended framework of support for people with Down syndrome and dementia\*

A series of basic topics and questions to highlight the importance of verbal and non verbal communication. It can identify flashpoints and raise sensitive issues for discussion with the emphasis on the opinions of the person with Down syndrome and dementia.

#### Sample framework topics and questions

- Identify who is taking the lead on future health and dental screening
- Note who is taking the lead for life story work
- Confirm that all staff will speak English if this is the person with Down syndrome's first language
- Record if tea, coffee, water or something else is preferred to drink with and between meals
- Record how pain is shown, both verbally and non verbally
- Record what kind of help is needed at mealtimes
- Does the person like to be hugged?
- Record how much food is usually eaten
- Note the range of communication methods currently used
- What words were used when a diagnosis or explanation was given to the person

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\* Wilkinson, H. and Watchman, K. (2010) *Down's syndrome and dementia: a framework for practice to support people with Down's syndrome and dementia living in generic care homes* in Hughes, J., Lloyd-Williams, M. and Sachs, G. (Eds) *Supportive Care for the Person with Dementia*, London, Oxford University Press.