

Frontotemporal dementia (FTD) – what does it mean for practice?



Be aware that a person with FTD may lack mental capacity. Care should be provided in line with the Mental Capacity Act. Consider carrying out an assessment if you are unsure of capacity.

If there is concern about cognition and behaviour at diagnosis explore these with the person and their family/carers as appropriate. Refer the person for a formal assessment in line with the NICE guideline on dementia (NG97).

Consider using the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) tool to assess patients for changes in cognition and behaviour.

The multidisciplinary team (MDT) should monitor cognition and behaviour and tailor the multidisciplinary assessment – adjusting the format if the person has cognitive or behaviour changes.

Advance Care Planning (ACP)

ACP should be discussed whenever the person is ready to do so. Think about discussing ACP with people at an earlier opportunity if you expect their communication ability, cognitive status or mental capacity to get worse.

Communication

Learning new technology may be difficult – consider using lower tech options if that is the case.

Support from an SLT is critical.

Allow extra time in sessions to communicate – may need to take along written and picture prompts to support assessments.

Communication methods and success are likely to change considerably over time, so adjustments are crucial.

Nutrition

For people with FTD who lack mental capacity – the MDT assessment should include the support they need from carers and their ability to understand the risks of swallowing difficulties.

Carers may need additional support with the cognitive and behavioural aspects of feeding eg over filling of their mouth with food.

For decisions about gastrostomy – a neurologist should assess:

- **The person's ability to make decisions and give consent**
- **The severity of frontotemporal dementia and cognitive problems**
- **Whether the person is likely to accept and cope with treatment**

Saliva problems

Consider glycopyrrolate as the first line of treatment for sialorrhoea in people with MND who have cognitive impairment, because it has fewer central nervous system side effects.

Respiration

Base decisions about **respiratory function tests** on consideration of the person's specific needs and circumstances such as:

- **their ability to give consent,**
- **their understanding of the tests,**
- **their tolerance of the tests and willingness to undertake them,**
- **the impact on family and carers,**
- **whether they are capable of receiving non-invasive ventilation (NIV).**

Before a decision is made on the **use of NIV**, the MDT together with the ventilation service should carry out an assessment that includes:

- **The person's capacity to make decisions and give consent**
- **The severity of dementia and cognitive problems**
- **Whether the person is likely to accept treatment**
- **Whether the person is likely to achieve improvements in sleep-related symptoms and/or behavioural improvements**
- **A discussion with the person's family and /or carers (with the person's consent if they have the capacity to give it)**