

Complexity in Practice

MAKING DECISIONS IN PRESENCE OF COGNITIVE CHANGE

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Julie

Julie – beautician and former model, mother and grandmother. Values her independence hugely. Lives alone in 1st floor flat. Mother died of MND

Changes to lower left limb and left arm also affected. Walking but balance is becoming impaired.

Com SALT referred to MND Team because of dysarthria, dysphagia and losing weight (9st 10lb – dropped to 9st).

Diagnosed with MND in Oxford Clinic Sept 22.





Changes to eating/drinking

Julie attends appointments and engages well with professionals.

Starting to struggle with food and liquids. Losing weight. SALT Ax highlights silent aspiration risk; and recommends level 5 mince and moist diet.

End Sept 2022 – SALT highlights concerns around rigidity in thinking; unusual beliefs about cause of MND and believes that it won't get worse. Declining fitting of PEG based on these beliefs.

Declined OT Ax – as “doesn't need anything”. Keen to be rehoused but only in Son's village.

Reflections:

- Early concerns about cognition and behaviour raised.
- Very demanding of Son – repeated messages/emails
- Slightly disinhibited in approach – physical contact/over familiar
- Messages to member of MND team increasing
- Concern around this aspect increased as chose not to use PEG. Often refusal to go along with recommended care /equipment raises questions about cognition/capacity where those who "go along with things" doesn't.
- Would an ECAS and/or MiND-B assessment have been helpful at this early stage?

Cognitive and Behavioural change

People with MND – Spectrum of Cognitive or behavioural impairment. 50% of people with MND have cognitive impairment. Symptoms can include:

Problems planning and sequencing

Difficulty prioritizing tasks or activities

Repeating things (words or actions)

Impulsive actions or words – without thinking through consequences/impact

Becoming disinterested in family or activities they used to care about

Insight (affected earlier than other types of dementia)

Judgement (affected earlier than other types of dementia)

Communication – ability to understand or express words can become impaired

Those with C9orf72 genetic expansion have higher prevalence of cognitive and behavioural impairment vs without C9orf72 expansion.



What about memory?

Memory is a complex skill requiring attention and concentration.

So although memory storage part of brain remains in tact, some aspects of forming new memories or storing new information may become impaired due to other reasons



NOV/DEC

With further discussion and support from the team Julie agrees to have PEG inserted (RIG due to anatomy). Inserted in Nov 2022

Struggling to use RIG by herself and becomes infected. Julie becomes constipated and has a fall. Julie is refusing carers to help her manage the RIG and refuses them entry to her home.

Seen by psychologist – inconsistent insight presented. Unclear what is anxiety/attention related cognitive challenge.

Daily emails from Julie to nurse:

“Do lots of flushes through RIGG it's my Life now .”

“I like the juices but both made me constipated it's getting me down .”

“I can do the flushes and clean the RiGG ok just have no life now .”

TEAM ARE CONCERNED





DEC/JAN

Julie continues to lose weight. She continues to struggle to eat and drink and starts to choke on her food – witnessed by family over Christmas. She is starting to feel dizzy. She is having episodes of constipation. She is having falls. Only having 360mls fluid per day. Refuses enemas as believes they are cause of constipation. Refuses to use walking aids –crawling around her flat.

Continues to purchase biscuits and other food that is hard for her to swallow. Demands Son takes her shopping and buys items when in the shop. Son feels doesn't know how to say no.

ACTIONS: Request care to start to help prompt with RIG Care and to encourage food and more fluids via RIG. Liaison with care agency about tips to engage with Julie (e.g. limit choice, be more directive).

Jan – Julie planning an independent trip to stay with friends in Margate. Team advised her against this due to not being able to eat/ constipation/ lack of care for RIG/ risk of falls. Alert Son due to concerns around this and advised to warn friends to reduce risk as much as possible. (Julie still went and had a fall whilst in Margate).

ACTIONS: Safeguarding alert raised requesting urgent social work input due to difficulties around care and support needs.



Who were involved

Julie

Care agency – for care of RIG

Son

Dietician

Speech and Language Therapist

MND Nurse

MND wider MDT Team including OT, Psychologist

Social Worker (not allocated but Duty Social Worker for advice pending allocation)

*Adult Community Mental Health Team declined referral.

FEB/MARCH

Professionals Meeting held. Agreed to complete formal mental capacity assessments around:

- 1/ Housing and support needs;
- 2/ Eating and Drinking orally
- 3/ Use of RIG for medication/supplementary nutrition/hydration).

Assessment determined Julie does not have capacity to make a decision around eating/drinking. Unable to understand the risks of choking/unable to retain advice related to safe choices/ refuses to use RIG for nutrition.

Best Interest decision taken that as eating is so important to Julie that eating at risk is reasonable - but that these should be Level 6 - soft and bite sized foods. Agreed for Dietician to remove any out of date food or at risk food from the property during visit.

Agreed Son will order Oakhouse foods from this category to have in the house; and try and remove risk foods from recent shop order

Care calls – twice a day to manage RIG – refuses to use it for food but is now allowing carers to enter the home and touch her RIG to help her manage this.



APRIL/MAY:

Activity monitoring installed to review pattern of behaviour. Identified Julie is not needing overnight care at present as she sleeps through 6pm-7am and gets up once or twice for the toilet independently.

CHC funding approved for care support QDS with 2x 2 hour long visits to enable meaningful activity

Very focused on going to Margate –Discussions from team about how we should support/risk manage these trips. ? With carer?

Decisions around use of RIG – Julie identified as lacking capacity. Best Interest decision taken:

Carers instructed to encourage and prompt Julie to have fluid flushes and Fibre drinks on each visit. Explicit instructions written for carers re minimum that Julie requires daily.

Nutrition and hydration to be encouraged through her RIG during every visit.

Julie is able to use her RIG herself, carers should be encouraged to empower Julie by offering her the syringe full of fluid, medication or feed for her to administer herself. Carers should always be clear with Julie what they are giving her. Julie refusing use of RIG for nutrition.

Advice: Call feed “NUTRITION DRINKS” or “FORTISIPS will allow acceptance of feed. With Distraction around video of Margate able to do feed with Julie’s engagement.



MAY / JUNE / JULY

Recommended NIV due to rising CO2

Working on encouraging Julie to attend "Holiday/Respite" at local nursing home. Visits one and likes it.

Jul - Getting Weaker – now 5st in weight. RIG fell out. Admitted to ward for replacement and re-feeding. Open to idea of moving to respite "holiday" home. Agreed with ward direct discharge to nursing home rather than home due to high risk at home.

Julie becomes less responsive on ward – hospital acquired pneumonia and type 2 respiratory failure

Nearly unconscious, moved to Respiratory ward and commenced on NIV





JULY

Respiratory function deteriorated. Needing NIV.

Distress with NIV being on – however, off the NIV she was breathless, fatigued, panicked asking for support and help. (Different masks/straps tried to maximise comfort).

Discussion among medics – options of sedation to tolerate NIV/Intubation - not appropriate.

Julie is a proud, image conscious and very independent person. Use of NIV is causing distress. However condition is deteriorating without NIV. Condition will continue to deteriorate.

Agreed discussion with family - to continue to offer NIV, but with a very low threshold for removing NIV and if refuses again and offering support to keep her comfortable and managing her breathlessness in other ways.

Julie became more sleepy and died peacefully in the hospital with her family around her.

REFLECTIONS

Specialist Nurse identified that with distraction of focusing on video and talking about Margate - Julie allowed nurse to use RIG to have nutrition and water without issue.

Changing the brand of product used – not Ensure but different enabled Julie to accept the nutritional drinks

If we had completed a baseline assessment (e.g ECAS and/or MiND-B) then we might have been able to catch this early and offer education to Julie and her Son.

Needs a whole team approach – one person can't be responsible for making complex decisions. Professional meetings useful to identify action plan and subsequent meetings to discuss best interests/least restrictive options.

Carer support: Tension of involving Son and him being involved and helping to manage condition vs strained relationship. Did we as professionals rely and ask too much from him in relation to his involvement? It became more straight-forward when we took lead as professional team on clear advice do/don't and enabled Son to have boundaries.

WHAT CAN WE DO: REMINDERS

Can't change the disease – the brain has been impaired.

Educate – abilities will be over-estimated by person and by carers due to often younger age group and physical ability.

Work to strengths

Assess environment – remove cues/stimulus to unwanted behaviour (Impulsivity may then be reduced).

Routine is important

Need support to stay on task.

Communication adapted (concentration/attention and language difficulties)

Need to adapt the care and support to the individual. The more we know them the better we can be at providing individual care