

Making Decisions About How I Eat and Drink

A Case Study

Grainne Tinney, Oliver Carey,
Isabelle O' Donoghue



Oliver



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Background Information

- Oliver is 37 years old
- Oliver has a supportive family network
- Oliver uses a wheelchair
- Oliver has cerebral palsy
- Oliver is non verbal (cannot speak)

Background Information

- Oliver spent his early childhood at home
- From 6 years of age Oliver attended a residential service
- Oliver lives in a nursing home
- Oliver goes to two day services
- Prosper Fingal
- I.W.A.

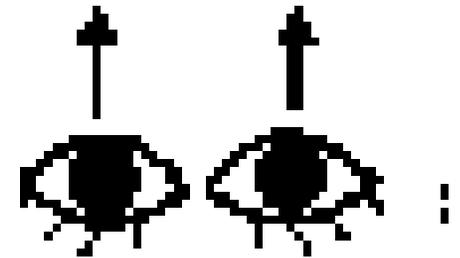


Early Services

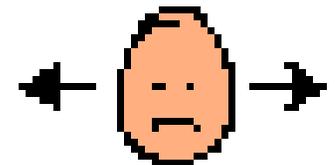
- Formal educational services were badly resourced
- SLT, OT and PT were also infrequent in the early years
- Oliver had a psychological assessment indicating functioning within the moderate range of intellectual disability (only non verbal measures used)

How Oliver Communicates

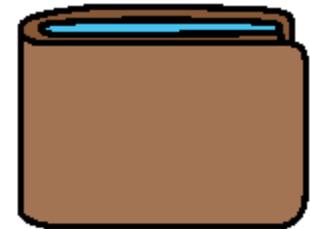
- Oliver says 'yes' by looking up with his eyes



- Oliver says 'no' by shaking his head



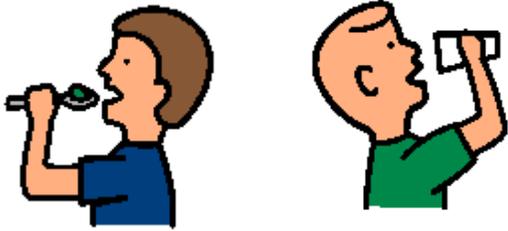
- Oliver has a communication book



- Oliver uses a communication device

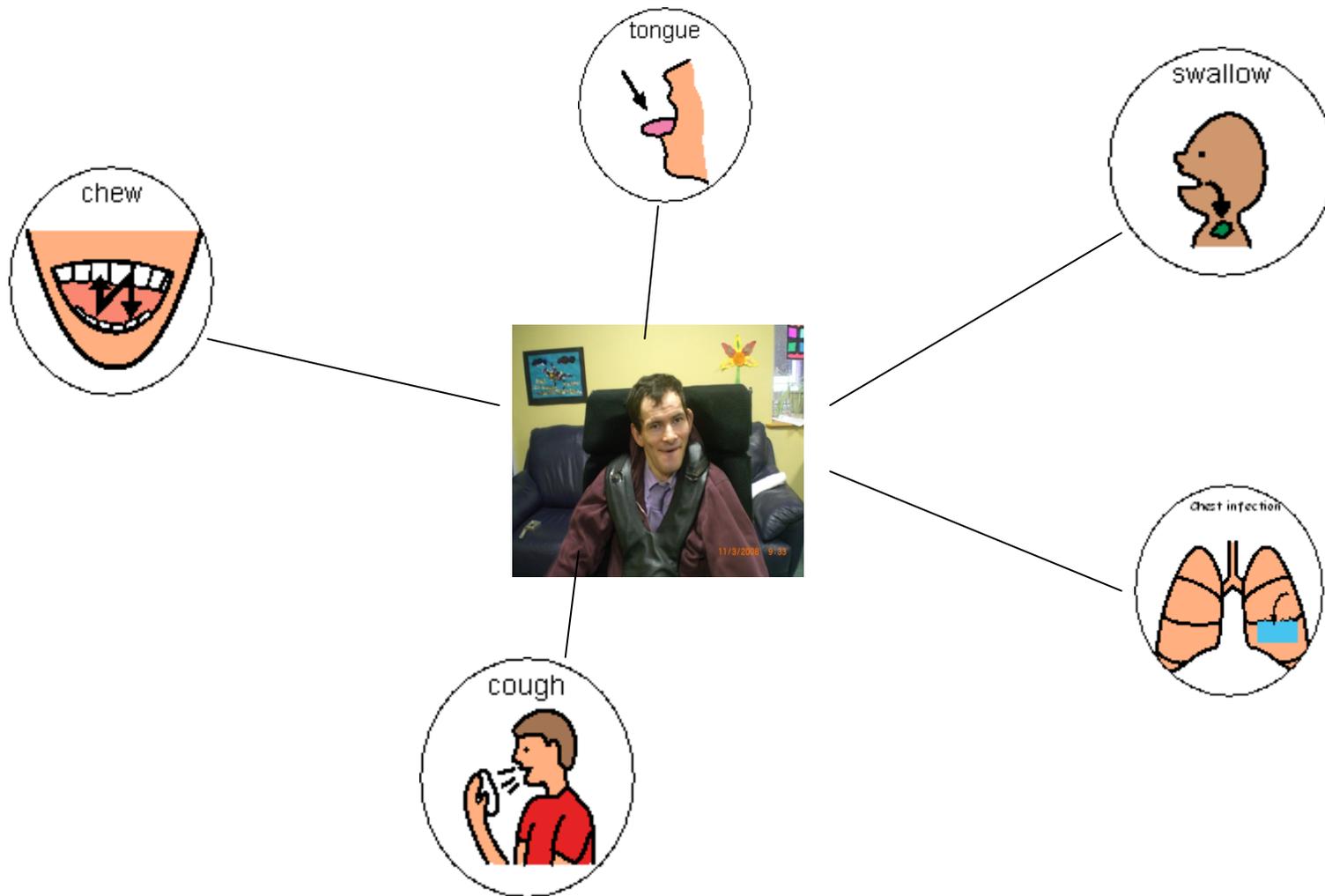


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Eating and Drinking

- Oliver has very limited tongue movements
- Oliver has no effective chewing skills
- Limited control over food and drink in his mouth
- A weak cough
- A delayed swallow
- Chest Infections



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Prosper Fingal

- Operates within a social model of disability
- Person centred planning plays a central role in service delivery
- With the exception of a small clinical team there is no medical team
- The need for the back up /expertise of the CRC was crucial

Other Service Involvement



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Other Service Involvement

- The CRC arranged for Oliver to have a video taken of his swallow.
- This video showed that food and drink was going into Oliver's lungs
- The CRC recommended a PEG tube only when issue of consent was addressed
- The CRC recommended that Oliver see a Psychologist

Recommendations for Oliver

- Utensils
- Positioning
- Pacing
- Thickening
- Consistencies



- Oliver had significant difficulties with his food /drink being modified in any way

Oliver's Agreement with Recommendations

- Oliver was confused about these recommendations and not happy
- The only way that Oliver could express his upset about the recommendations and other issues was to refuse food
- This was a way of having control

Family and Staff Concerns

- Weight Loss
- Chest Infection
- Oliver's frustration

- Once there was solid confirmation of the extent of Oliver's eating and drinking problems
- That's when the real challenge presented

Our Challenge As an Agency

Supporting Oliver to understand and accept

- the existing recommendations for oral feeding
- How to determine Oliver's ability/capacity to demonstrate informed consent or refusal

Dilemma of Multi Agency Involvement

- Oliver attends two day services and lives in a residential nursing home
- It was difficult to ensure that recommendations were the same in each place
- Oliver was confused as he thought blended food indicated he was like a child

Oliver



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The Questions To Be Answered

- Does Oliver understand his own eating and drinking problems?
- Can Oliver learn new information so that he can make a decision?

Previous Assessment by Psychology and Speech and Language Therapy

- These were of little use to us in the process
- Previous assessments were non verbal only
- One of the psychological assessments was a rating scale
- This did not give information about a person's understanding

Capacity and Consent Issues

- To give meaningful consent a person has to:
- Be appropriately informed about the decision in question.
- Have the ability (capacity) to be able meaningfully and freely to give or withhold consent.
- Must be supported appropriately to make decisions.
- The individual has the right to make decisions that could be considered unwise or eccentric

Capacity and Consent

- When assessing a person with learning disability to consent for a particular investigation or intervention it must be remembered that this "capacity", if present is only valid for the procedure proposed.
- Capacity needs to be repeatedly assessed for each proposed intervention.
- If a person does not have capacity the approach taken is to have a meeting of all relevant people to make a decision based on the person's best interest

Determining Capacity: What Has Been Done Before

- Based on level of intellectual disability.
- Based on rationality of decision.
- Functional-How good is match between ability level and demand of the decision making process.

Determining Capacity

- Clinical assessment.
- Court decision based on evidence and expert opinion.

Clinical Assessment.

- Adapt to individual.
- Tailor questions.
- Alternative methods of presenting material.
- Time to review.
- Encourage questions.

Leyden 2006

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Clinical Assessment

- Show:
 - Rationality.
 - Knowledge of procedure.
 - Voluntariness
- Level of ID important, but in conjunction with these factors.

Assessment of Capacity

- Recent Study (2010)
- Ability to process and recall information generally.
- Ability to process and recall information about procedure.
- MDT assessment of communication skills, mental health status and ability to understand that a decision is to be made.

What We Found Useful

- Oliver can answer yes/no questions
- Oliver can use his book to talk about people , events , news etc
- Oliver has an interest in politics and what is happening in the world
- Oliver can make his needs known

What We Found Useful

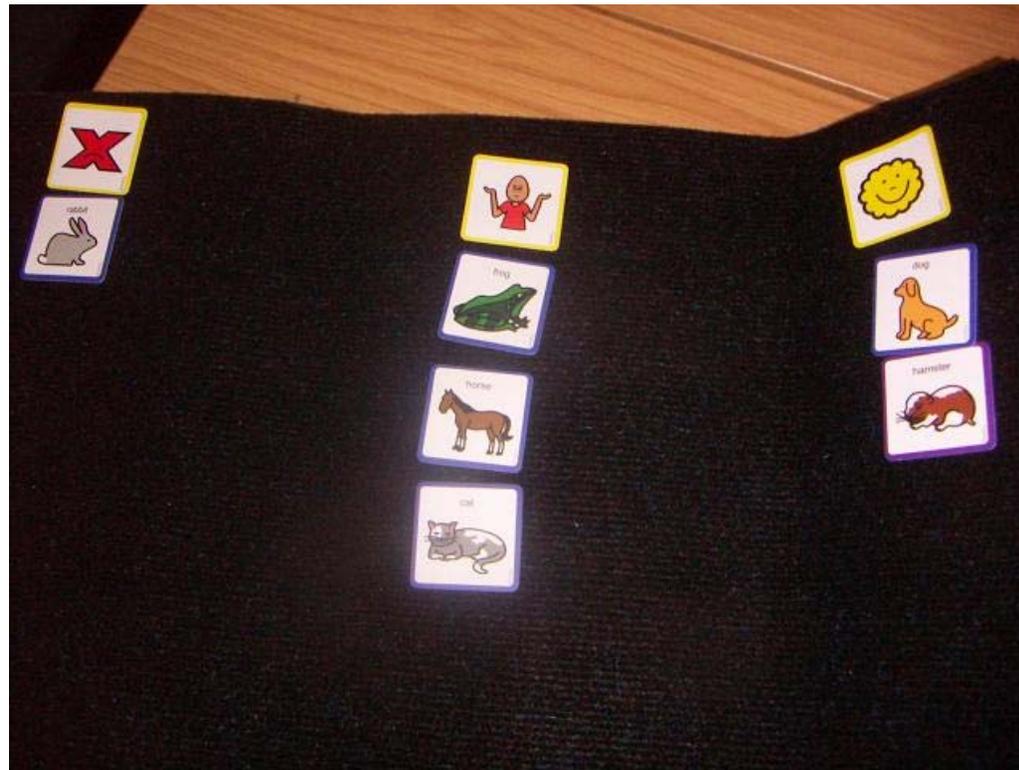
- Oliver has a good functional understanding of his environments and personal circumstances
- Oliver can recall information from previous experiences
- Oliver learnt to use a high tech communication device

Multiple Choice Reasoning skills



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A Communication Mat



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Three Phases

- Establish what Oliver understands using Oliver as his own baseline
- Facilitate Oliver in learning what he needs to understand
- Capacity

The Process

- Introduced the mat with the symbols *yes*, *no*, *I don't know*

yes



no



I don't know



- Oliver's responses were photographed



- Oliver was supported to learn the symbols/vocabulary that he did not know

The Process

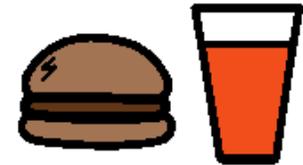
- Following week tested to see if knowledge was retained
- Oliver did not always recognise the pictures when presented without the label
- Clarifying each picture with the word often helped.
- In some instances it made no difference as Oliver did not recognise the vocabulary/terminology

- Also multiple choice responses were used for topics that required Oliver to give more specific information.
- Choices of responses were presented in a visual format on the mat enabling Oliver to make responses with the vocabulary available
- There was no other way around this issue

- Constant reviewing to check that he was understanding was conducted
- Having 2 people working with Oliver meant 1 person couldn't lead or prompt him so responses were **his own**, and therefore valid

Topics Covered

- Body Parts
- EDS body parts
- Functions of EDS body parts
- Food likes /dislikes
- Why certain foods are not appropriate



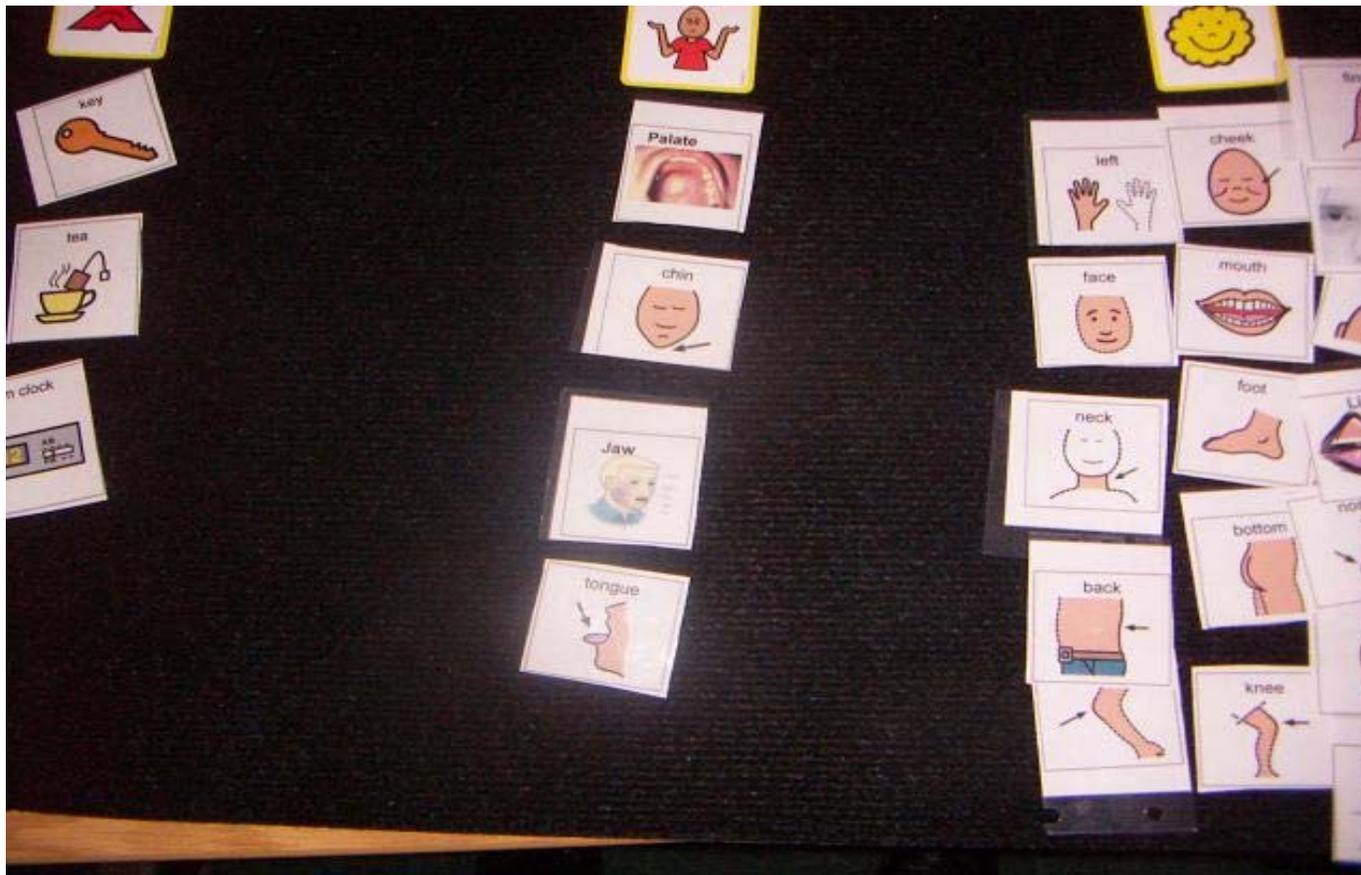
Topics Covered

- Advantages of PEG feeding
- Disadvantages of PEG feeding

- What happens in an operation

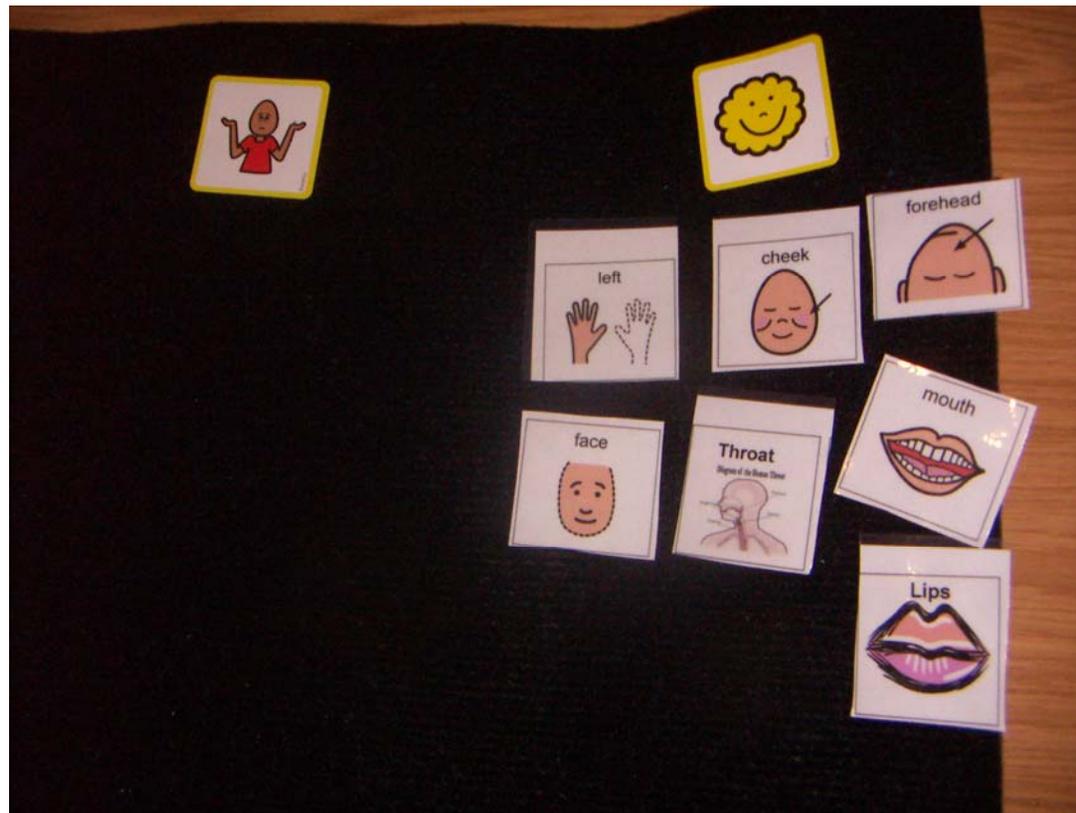


General Body Parts



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EDS Body Parts



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Body Parts Used in EDS



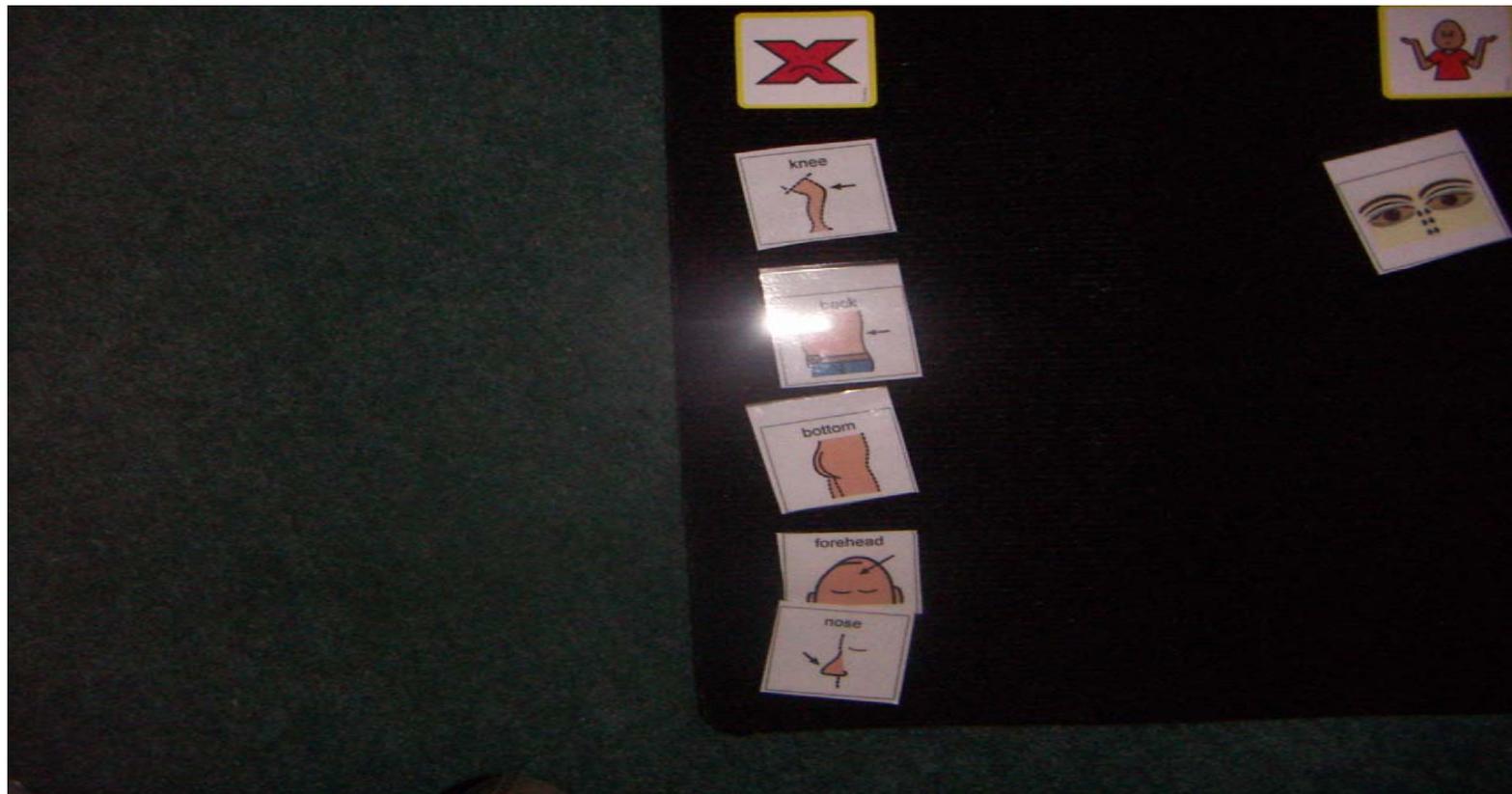
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EDS Body Parts

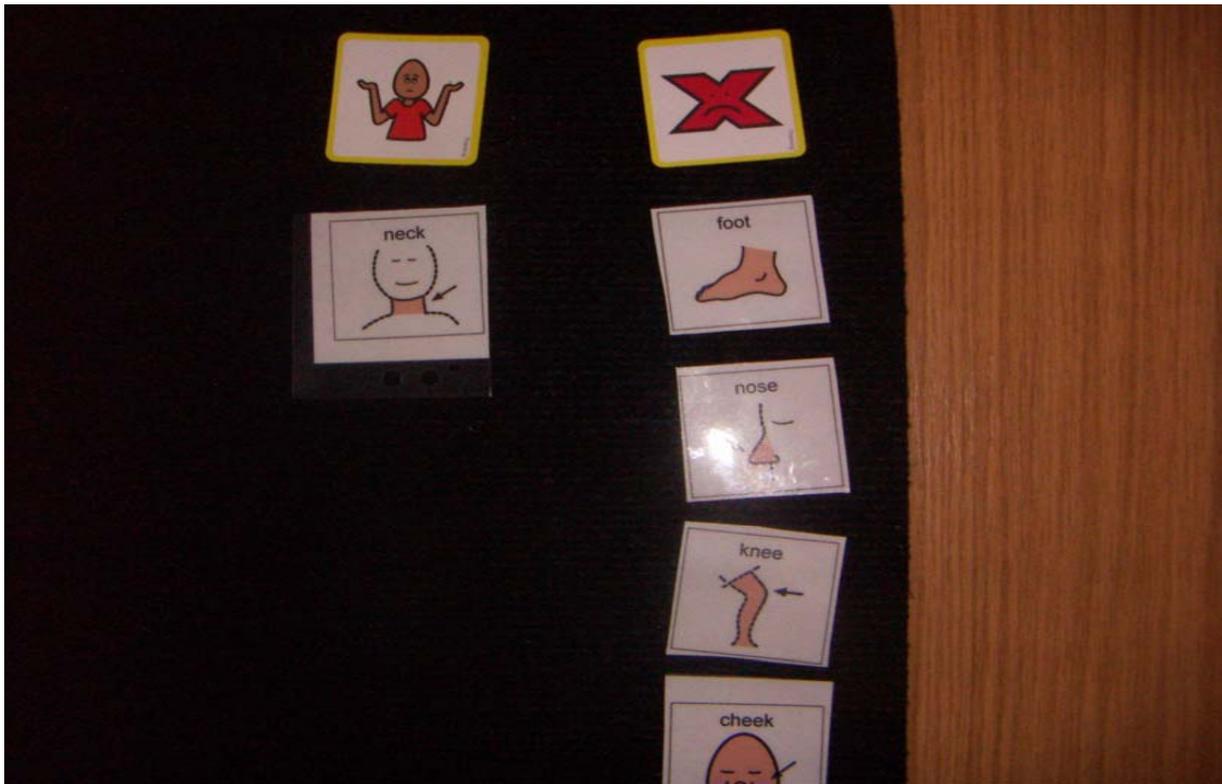


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Body Parts Not Involved in EDS

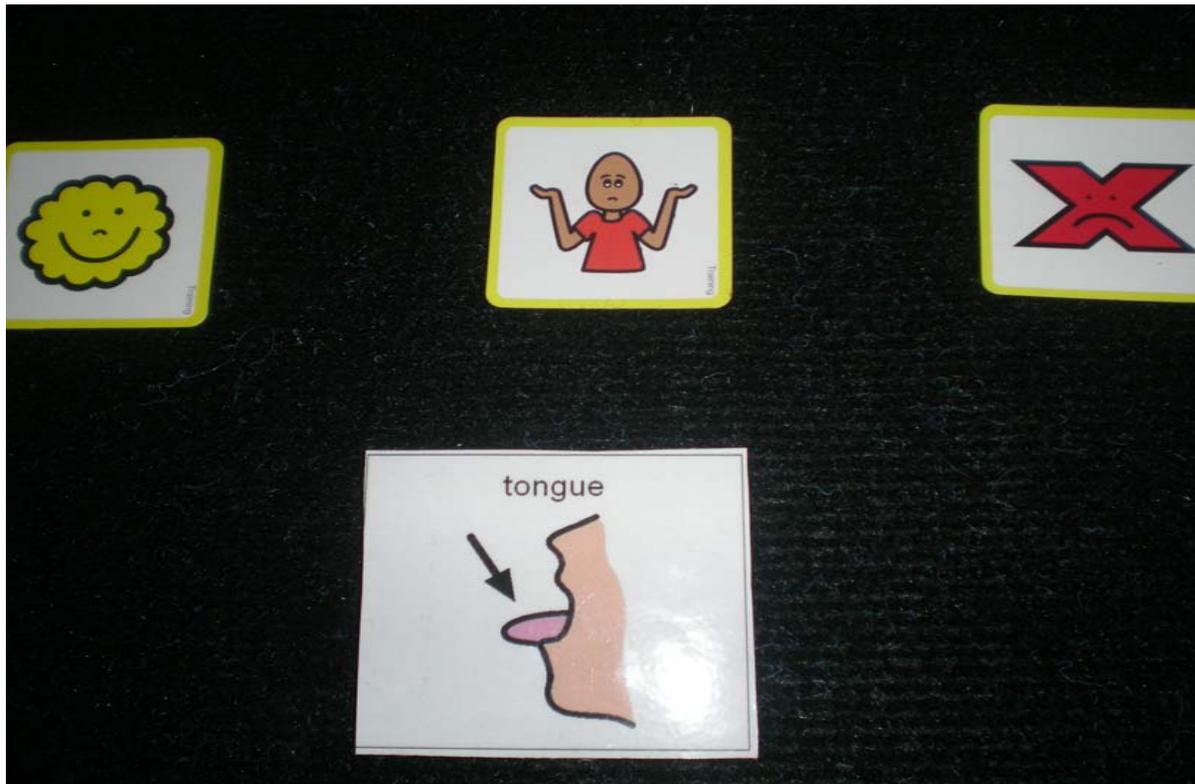


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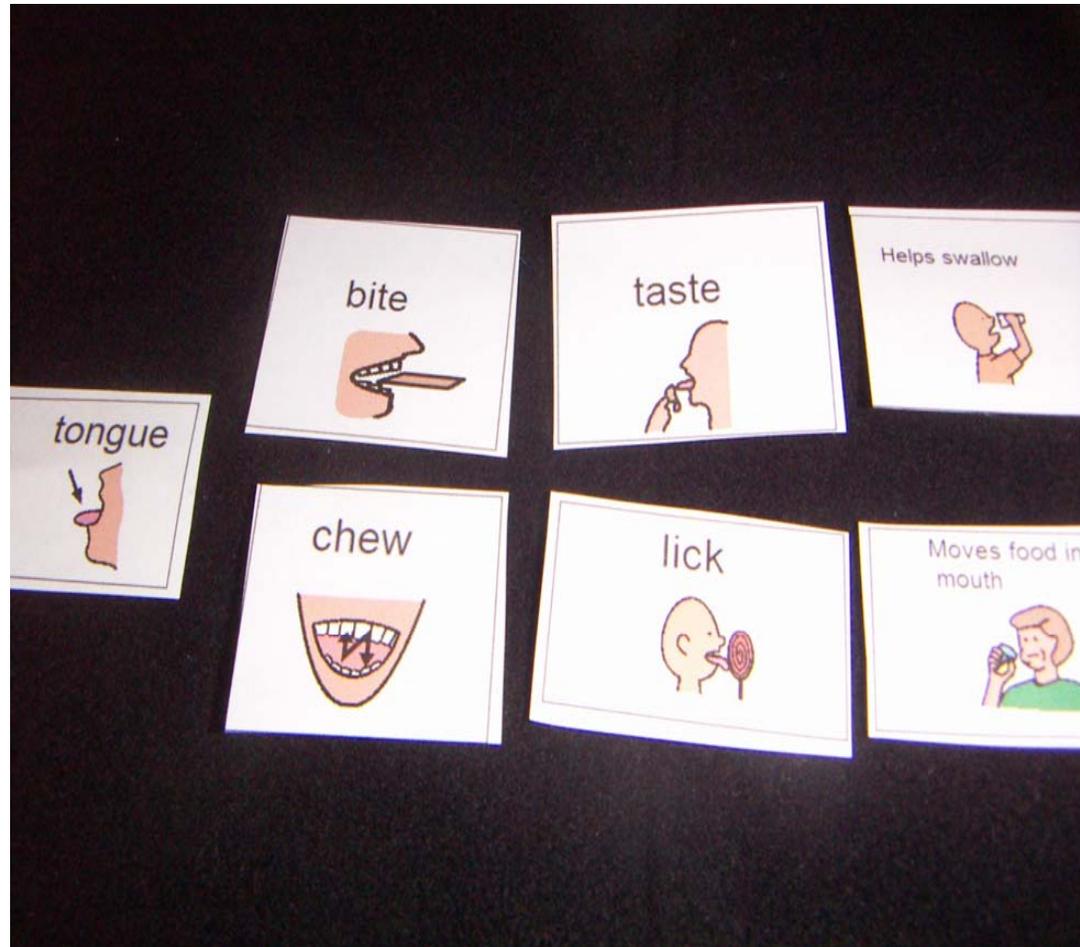
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Function of the Tongue



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Multiple Choice for EDS Functions



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Functions of Body Parts

- Oliver did not know how his mouth worked he had some understanding about teeth , unsure of tongue, palate, lips
- Oliver was facilitated through the use of visual aids and demonstration where possible to learn these
- To start to raise awareness of his own limitations on what mouth could and could not do
- In particular lips, teeth,tongue cheeks, palate were covered

Food Likes /Dislikes

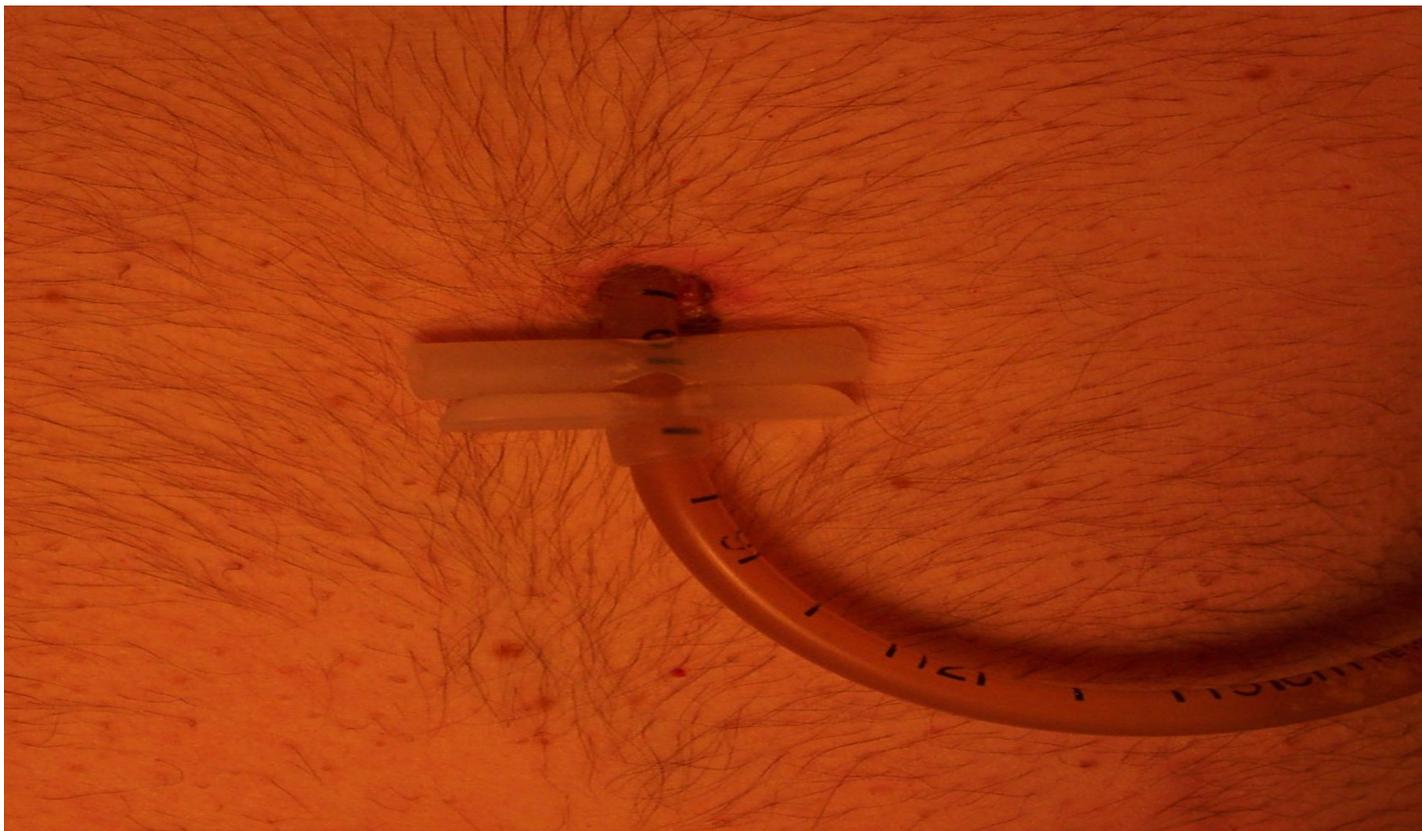
- Using his communication book and the mat we discussed his likes and dislikes
- Explanations were given about certain foods he could not eat.
- Oliver could then relate this back to his understanding of how his mouth works

PEG Feeding

- Advantages/Disadvantages
- What happens in an operation
- Infections
- Tube feeding examples



Peg Feeding



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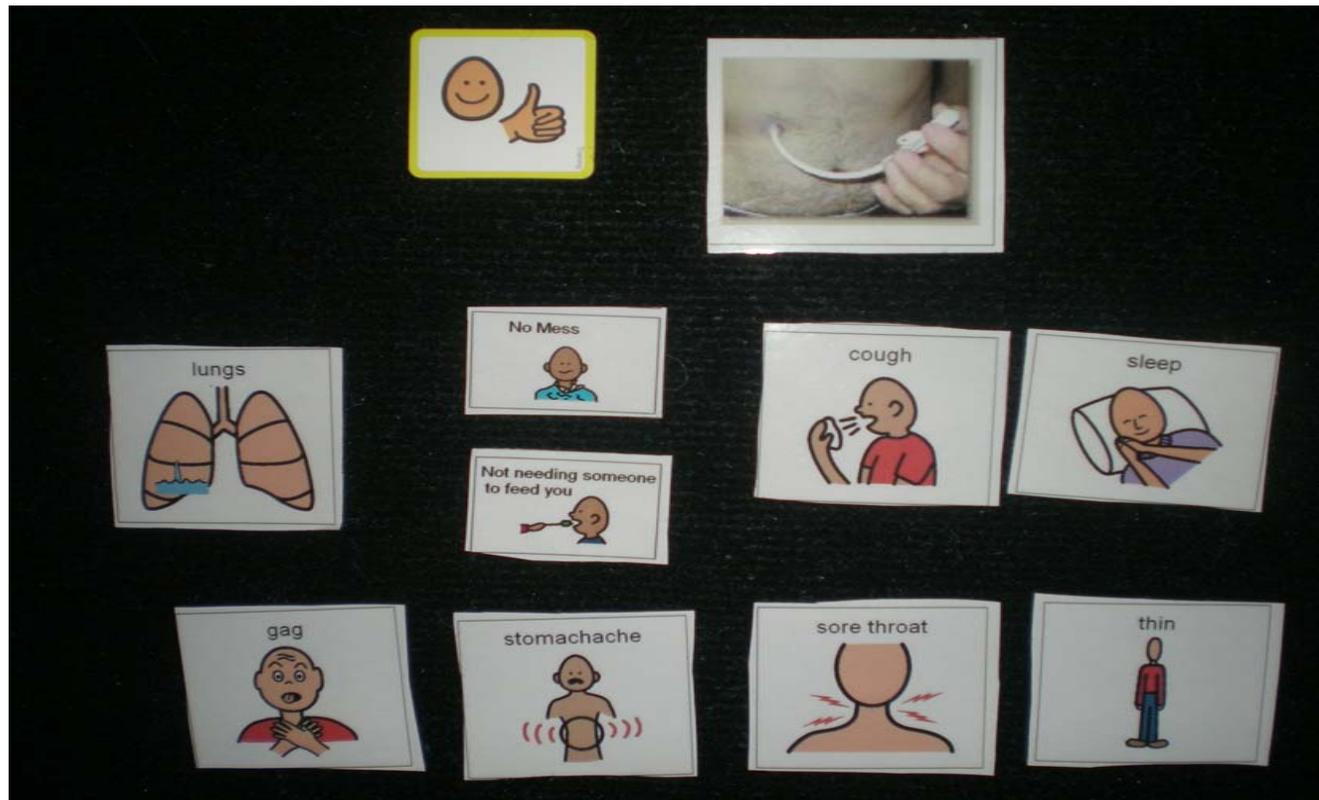
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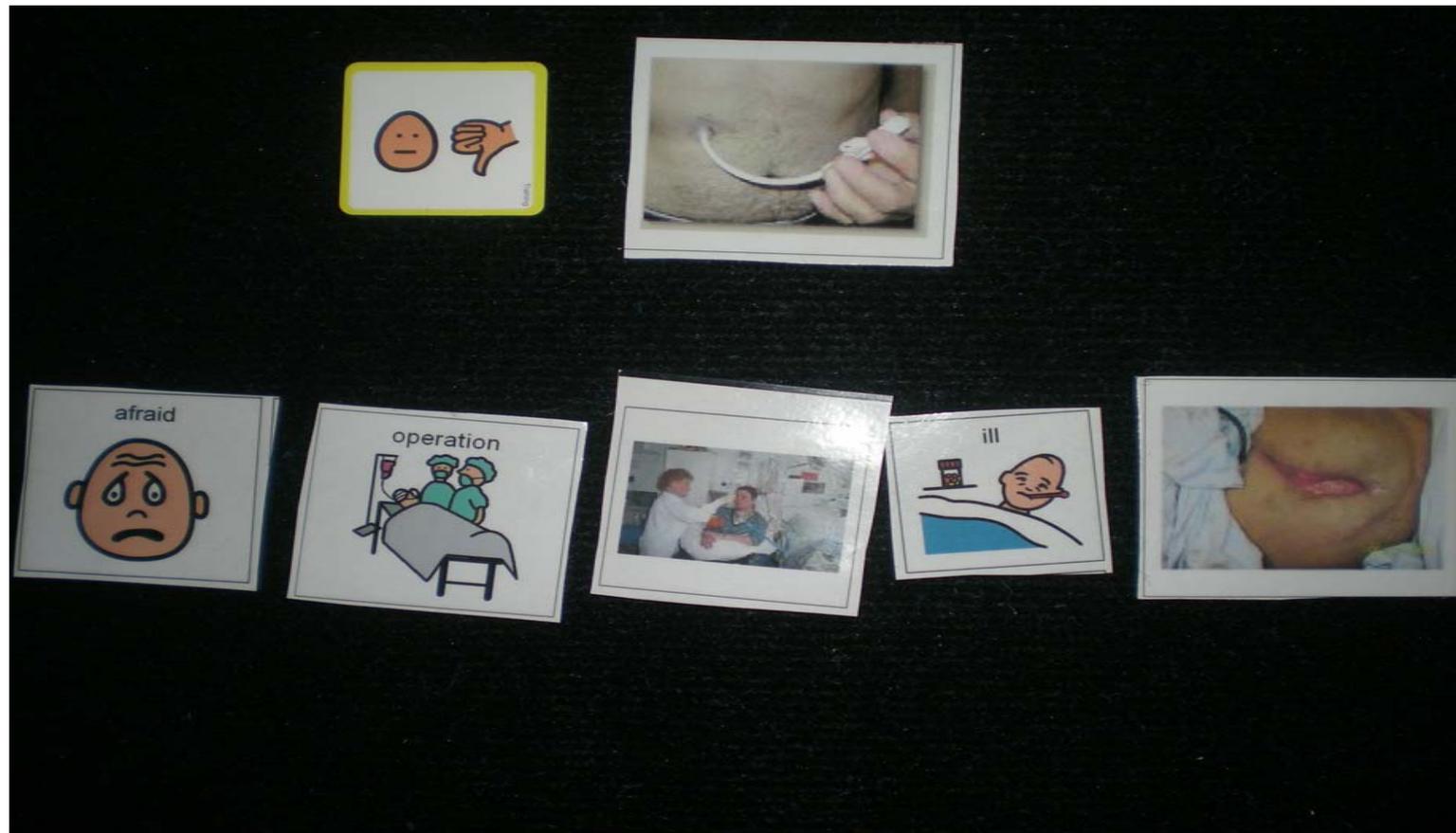
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Advantages of PEG Feeding



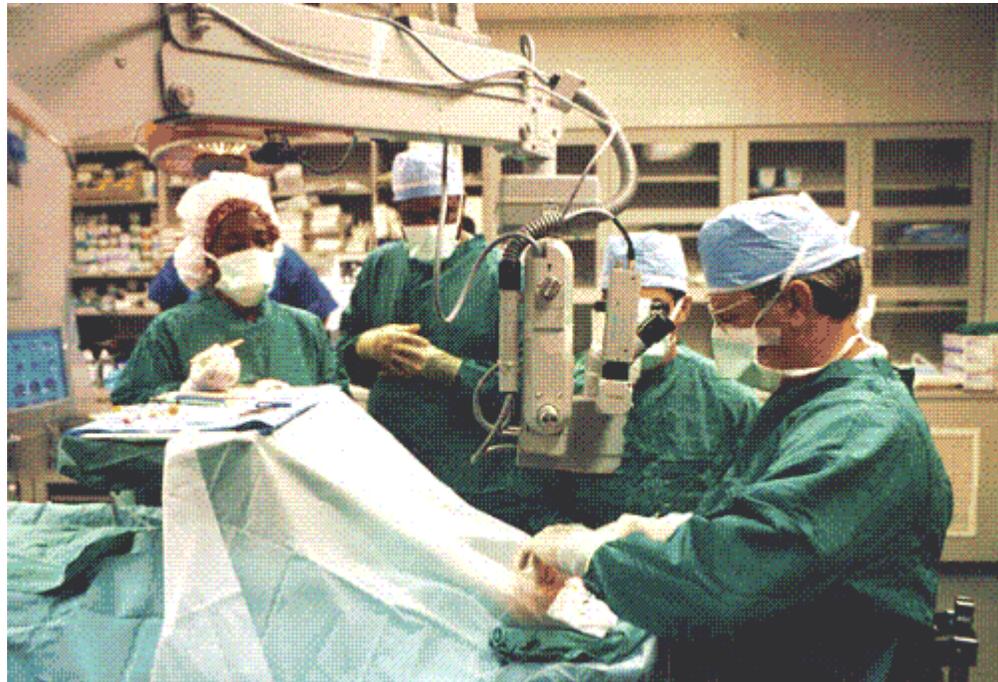
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Disadvantages of PEG Feeding



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What Happens In An Operation



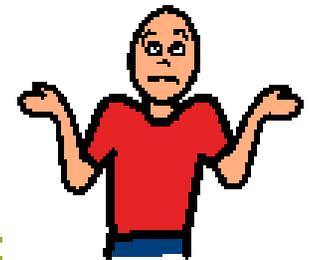
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Joint Working With Psychology

- This was the first time that Prosper Fingal had undertaken this type of work
- It is important to say that no standardised assessments were used but we were fully aware of previous assessments conducted
- Represent an under estimate of Oliver's ability

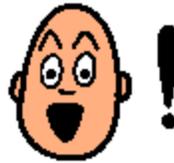
What We Learnt About Oliver

- Oliver clearly indicated when he didn't understand or needed something explained again
- Oliver requested more information on particular topics
- Oliver used 'I don't know' appropriately



What We Learnt About Oliver

- Oliver was shocked when he learnt about the dangers to his health about eating everyday food



- Oliver was surprised on seeing a tube inserted in a persons stomach

What We Learnt About Oliver

- Oliver remembered most new information given to him
- We found out that Oliver's protests were not because he didn't understand, but more that he didn't want to accept what he was hearing.
- This relates more to his emotional level

What We Learnt About Oliver

- Oliver was more receptive to discussing issues and very co operative throughout the whole process
- When asked about his opinion on PEG much more amenable to this as a consideration

Oliver Now

- Oliver is agreeable to thickening of his drinks
- Oliver eats smooth blended food
- Oliver will remind people of his thickener if they forget

Conclusions

- Standardised assessment would not yield the answers to capacity for consent
- No concrete support in the literature
- An individual approach was deemed necessary
- Not an exact science

Conclusions

- Oliver has shown the ability to understand his eating and drinking problems
- Oliver understands how the problems can affect him
- While he has gaps in his understanding he still has demonstrated the capacity to learn about specific topics
- Oliver is more informed to make decisions in relation to PEG feeding and how he eats and drinks

Finally..

- There is a need for more work and research in this area
- A multi disciplinary team working together in supporting people to make decisions is very important
- Especially for people for whom communication is a challenge

Literature Review

‘Helping People Make Decisions About Peg Feeding’ *RCSLT Bulletin 2003 No.618*

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Literature on Compliance

Chadwick,D.D, Jolliffe,J.& Goldbart,J.(2002)

Carer Knowledge of Dysphagia guidelines

International Journal of Language and Communication disorders

Chadwick,D.D., Jolliffe,J. & Goldbart,J. (2003)

Adherence to Eating and drinking Guidelines for Adults With Intellectual disabilities and Dysphagia

American Association on Intellectual and Developmental disabilities

Literature on Capacity

- Decision Making Capacity in Cognitively impaired individuals (2008) *Neurosignals*
- Medical Decision Making Capacity in Patients with Mild Cognitive Impairments(2007)
American Academy of Neurology

Literature on Capacity

- Demystifying the process? A multidisciplinary approach to assessing capacity for adults with a learning disability(2010) *Br. Jour. of Learning Disabilities*
- Mental capacity and Guardianship Bill 2008