

The Oxford ALS Nutrition Clinic: Improving the enteral nutrition pathway for patients and carers

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Why does it seem so complicated?

Challenges for PALS and service

- **Outcomes**

- **Processes**



- **Difficult decision**

(Vesey, Leslie, Exley 2008)

Aims of audit

1. Compare **pre** and **post** introduction of a dedicated Nutrition Clinic
2. Evidence PALS and carers' perspectives, decision-making process

Methods: Pre + post comparison using King's guidelines

Topic	Pre-nutrition clinic	Post nutrition clinic
1. Gastrostomy feeding may prolong life but it will not halt ALS		
2. Oral feeding whether it is safe to continue to do this		
3. Psychological and QOL issues		
4. The need for carers to be involved and training for pts and carers		
5. Risk of aspiration with continued oral feeding		
6. How the procedure is carried out		
7. Surgical risks and morbidity related to the procedure		
8. Community/hospital support following discharge		
9. Pump and bolus feeding methods		
10. Practical issues		
11. Window of opportunity		
12. Length of hospital stay for insertion of PEG/RIG		

Pre-nutrition clinic

Patient	Age	Sex	Diagnosis	Time between onset of symptoms + diagnosis (months)	Known Cognitive Impairment	Time between diagnosis + insertion of PEG/RIG (months)	Attended MND Nutrition Clinic + comments	PEG/RIG
A	58	F	ALS BO	7	N	27	N	PEG
B	75	M	ALS BO	9	N	6	N	RIG
C	69	F	ALS BO	5	N	2	N	PEG
D	52	M	ALS BO	10	N	7	N	RIG
E	57	F	PLS	26	N	44	N	PEG
F	41	F	ALS BO	5	Y	4	N	PEG

Pre-Nutrition clinic

- General comments positive regarding explanations of EN given



BUT...

Pre-Nutrition clinic

Psychological + QOL issues

- 3/6 PALS:

'it could be explained a bit better just to say it is going to have an impact... you do imagine it's bigger than it is' (C)

'even giving your husband a hug is actually quite problematic... there it is right in the middle' (A)

'I'd hoped it would show less than it does' (D)

Pre-Nutrition clinic

The need for carers to be involved

4/6 PALS/carers

'it does all fall on the carer and erm maybe to just explain a bit more what the carer has to do... it's all time-consuming and I wasn't quite aware' (D's carer)

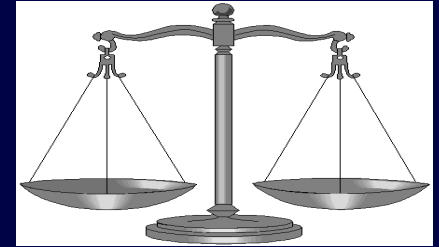
'if ... the carer could be shown beforehand what to expect... you get your mind prepared and ready for it, and you don't get quite so overwhelmed by it' (A)

'this wasn't talked about' (E)

Pre-Nutrition clinic

How the procedure is carried out and Surgical risks + morbidity related to the procedure

'I had no idea what was about to happen' (B)



4/6 PALS unexpected severe abdominal pain

'it was like having a baby...the stress of that pain... I was crying with pain even when I went home' (C)

'extraordinarily painful...nobody warned me that it might be painful' (A)

Pre-Nutrition clinic

Community/hospital support following discharge

4/6 PALS

'we were given no information at all...because everything is...Monday to Friday'
(D's carer)

'we spent two days not knowing who to contact' (A)



Pre-Nutrition clinic Pump and bolus feeding methods

'overwhelmed me with all the feeding, about you can do this and do that'
(B's carer)

thought PEG feeding
'had to take much longer than it does'
(F)

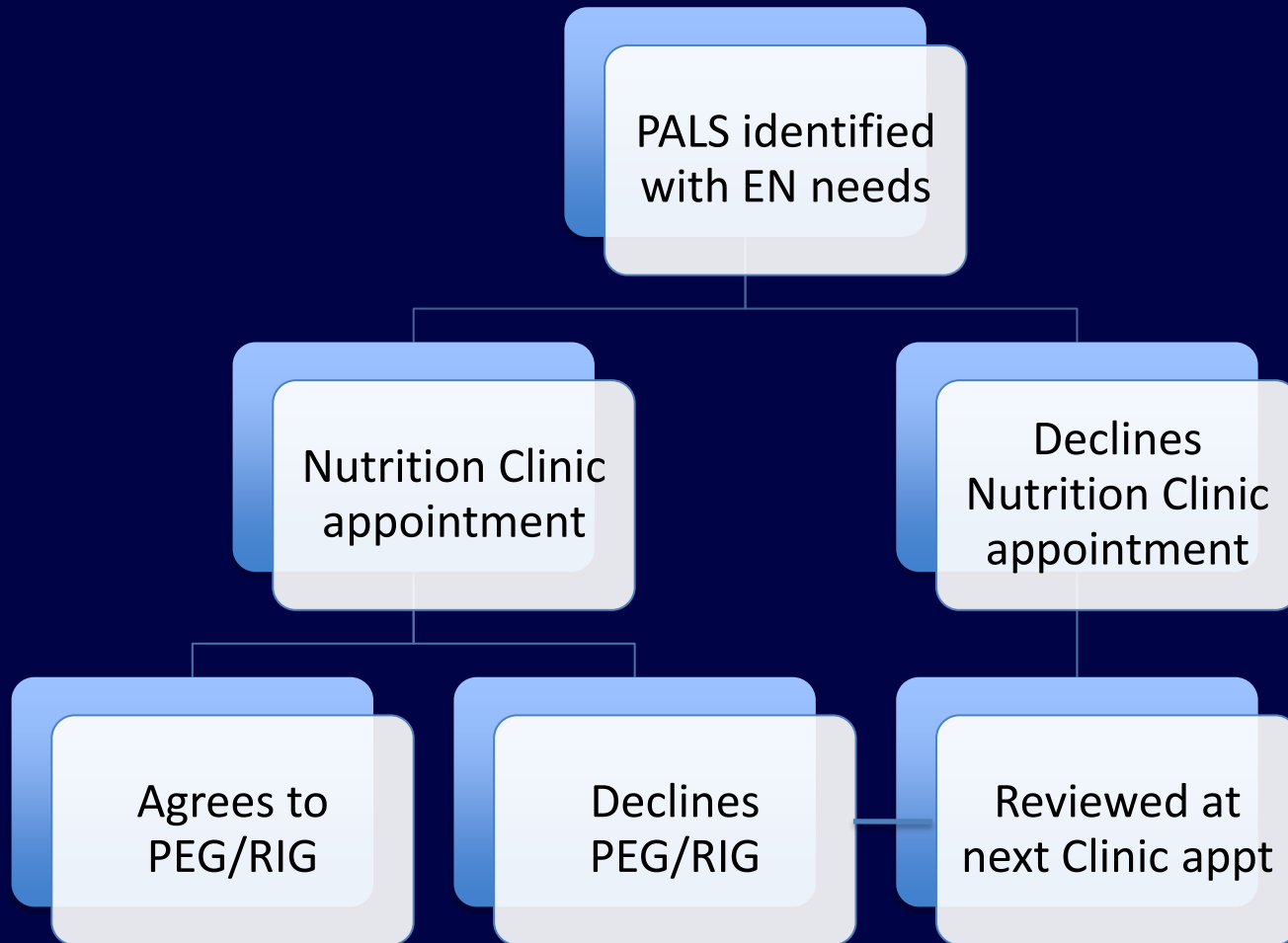
Pre-Nutrition clinic

Window of opportunity

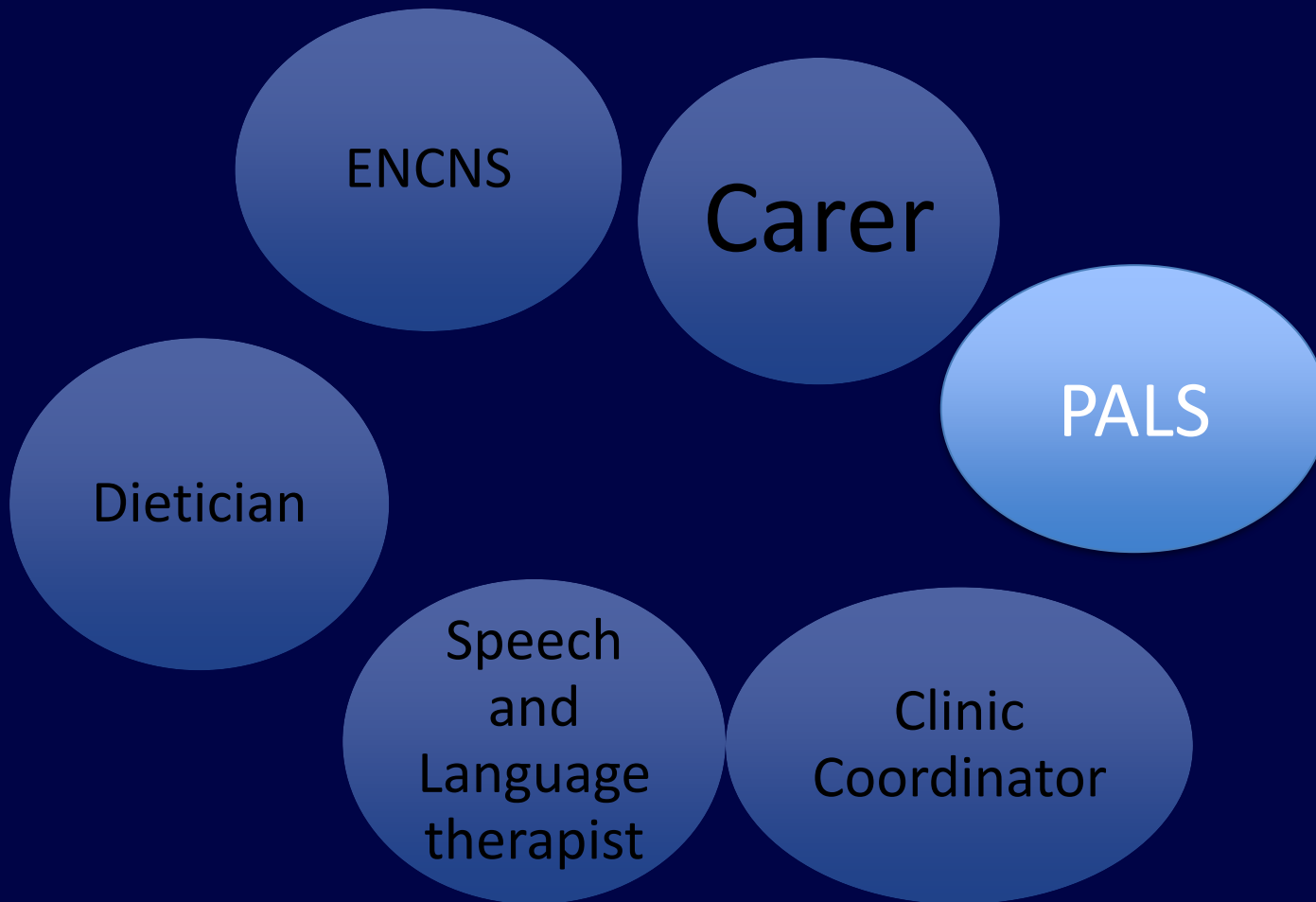
Length of hospital stay

'staying away in hospital is quite a big thing, particularly when you have dependencies and you have routines worked out to make things comfortable ..we might have been more prepared for that' (A)

The Nutrition clinic



MDT Nutrition clinic: 'effective communication requires time, a commodity often in short supply'



1. b) Post-nutrition clinic

Patient	Age	Sex	Diagnosis	Time between onset of symptoms + diagnosis (months)	Known Cognitive Impairment	Time between diagnosis + insertion of PEG/RIG (months)	Attended MND Nutrition Clinic + comments	PEG/RIG
G	62	M	PLS	37	N	N/A	Y Declined PEG/RIG	N/A
H	60	F	ALS BO	13	N	2	Y	PEG
I	58	M	MSA	36	Y	23	Y	PEG
J	81	M	ALS BO	5	N	3	N Declined	PEG
K	65	M	PBP/ALS BO	5	N	6	Y	PEG
L	65	F	ALS BO	4	N	13	Y	PEG
M	64	F	ALS with cognitive involvement	24	Y	9	Y	PEG
N	59	F	ALS spinal onset	8	N	4	Y	RIG

Post-Nutrition clinic: information complete for 8/12 topics

Topic	Pre-nutrition clinic	Post nutrition clinic
1. Gastrostomy feeding may prolong life but it will not halt ALS	YES	YES
2. Oral feeding whether it is safe to continue to do this	YES	YES
3. Psychological and QOL issues	NO	YES
4. The need for carers to be involved and training for pts and carers	NO	NO
5. Risk of aspiration with continued oral feeding	NO	YES
6. How the procedure is carried out	NO	YES
7. Surgical risks and morbidity related to the procedure	NO	NO
8. Community/hospital support following discharge	NO	NO
9. Pump and bolus feeding methods	NO	NO
10. Practical issues	NO	YES
11. Window of opportunity	NO	YES
12. Length of hospital stay for insertion of PEG/RIG	NO	YES

Post-Nutrition clinic

Room for improvement on 4/12 topics

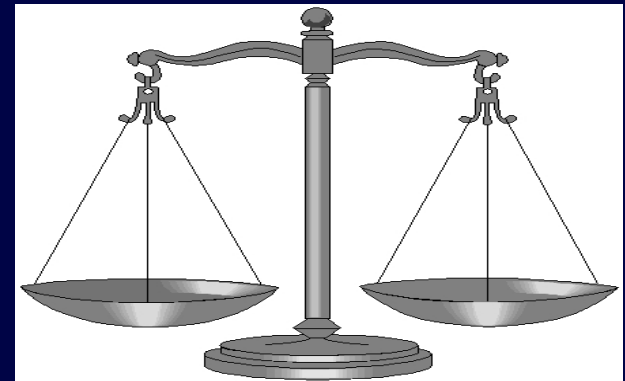
The need for carers to be involved and training for pts and carers

'cleaning and turning...I wasn't aware to start with it had to be done' (I's carer).

Post-Nutrition clinic

Surgical risks and morbidity related to the procedure

- only the 'breathing risks' (H)
- 5/7 took Buscopan



Post-Nutrition clinic Community/hospital support following discharge

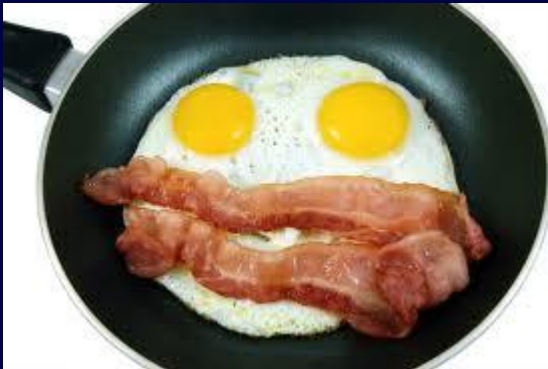
'The problem I had is you see so many people
you lose track, they overlap quite a lot'.



Post-Nutrition clinic

Pump and bolus feeding methods

'I think he thought he would be putting bacon and egg down it' (K's carer)



Audit results 2.

PALS and carers' decision-making

- *Necessity Vs. body image*
- *Influences 'they guided us but it felt right'*
- *Opportunity for discussion*
- *Reflection: satisfied with choice*
- *Carers - reduced anxiety*



Audit results 2.

PALS and carers' decision-making

*Declining insertion/reluctance to use
gastrostomy*

'I didn't fancy the intrusion, the daily care'

'when I can't enjoy my food orally it gets to the stage then you think well what's the point?'

Limitations

- Small sample ?generalisable
- Researcher effect ?limited criticisms
- 1 snapshot in time only
- Cognitive impairments not formally assessed

- Resources to deliver?

Conclusions

- Consider dedicated MDT nutrition clinic
- Time and open discussion for decision-making
- PALS and carers feel more prepared and in control
- Responsive service shaped by PALS experience

Thank you!

Any questions?

