Economic costings – Professional Questionnaire G-PATH Support: Gastrostomy feeding and psychosocial support [14/04/40]

Your service has been selected for a case study in the G-PATH Support study, funded by the National Institute for Health Research (NIHR), Health Services and Delivery Research.

What is the purpose of this survey?

This survey is aimed at staff who work with children with neurodisabling¹ conditions. The purpose of this survey is to collect information about the psychosocial support your service may offer. As part of this study we aim to estimate the cost of services providing psychosocial support to children and families. This will allow us to calculate the potential cost benefits of providing psychosocial support as a future intervention alongside current care.

By psychosocial support we mean:

- ♦ The provision of emotional or psychological support in coming to terms with the need for a gastrostomy feeding tube and which offers parents, young people and children the opportunity to explore any concerns about feeding, the values they attach to the meaning of food, eating, feeding by mouth and/or gastrostomy feeding in the context of child and family and their everyday lives in both the decision-making phase and post-surgery. We would also include practical support in managing new nursing procedures.
- ♦ By structured support we mean support that is consistently provided as part of a care plan or care package. This may be during the decision-making phase, the period immediately after surgery and in the longer term. It may be offered by a designated professional, member of the multidisciplinary team or lay person/parent. Examples of support may include:
 - Discussions around different feeding options for children
 - Support to children and families when making the decision to have a gastrostomy placed or removed
 - Offering emotional support before and after gastrostomy tube placement
 - Emotional support to children and families including managing expectations about the benefits of a gastrostomy and dealing with any complications of the procedure
 - Practical support in learning new nursing procedures
 - Other related problems that could be of a psychosocial nature related to feeding and a gastrostomy e.g. where parents request to meet to express regret at the decision, disappointment or ask for it to be removed. It may also include psychosocial aspects relating to maintaining or (re)introducing oral feeding where this has been requested post-surgery, advice on blended feeding etc.
 - Psychosocial support may be provided formally (e.g. by a designated professional or as part of a care plan/package) or informally (as part of routine care).

What will I be required to do?

1

Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified' [Morris et al 2013]. Examples are children with cerebral palsy. Other groups of children would include those with Down's syndrome, Attention deficit hyperactivity disorder, Autism spectrum disorder.

If you decide to take part in this element of the research, you will be asked to fill in the survey and answer questions about the psychosocial support your service offers.

What happens to my completed survey and data?

The data will be kept confidential, we will present it as group data, and we will also use pseudonyms to protect confidentiality when reporting data.

Please fill in your details/answer the questions below

	About You
1.	What is your job title?
2.	What is your grade?
3.	What is the name of your service?
4.	Please tick the box below which best describes your service
	☐ Child Development Centre
	☐ Home enteral nutrition team
	□ School based service
	□ Paediatric disability service/team
	□ Other (please state)
5.	Does your service have a specific budget for providing psychosocial support?
	Yes (please specify) £ total / £ per child
	No
	I don't know

About Children & Gastrostomy Feeding Tubes
6. In the last 12 months
a) How many children under your care with a neurodisabling condition have been
considered for a gastrostomy?
b) How many children were referred to a specialist centre for an opinion about the suitability of a gastrostomy?
c) How many children had a gastrostomy placed?
d) How many children had a gastrostomy removed?
e) How many children had a gastrostomy reinserted?

7. Please choose up to 4 children in your care in the last 12 months (you do not need to identify the child by name) where you have discussed any aspects of feeding including where a gastrostomy was considered, inserted or removed and estimate the number of hours you have spent providing psychosocial support to both children (where appropriate) and their caregivers

Child		Approxim	ate hours			
		spent in last 12		Approxim	nate hours	
	Did this child have a	mont	hs on	spent p	roviding	
	gastrostomy	psychosocial support		psychosocial support		
	placed?	prior to gastrostomy		following		
		insertion/making the		gastroston	ny insertion	
		decision				
		Child	Caregiver	Child	Caregiver	
EXAMPLE	YES	1	2.5	0	3	
1						
2						
3						
4						

	Deli	vering Psychoso	cial Support			
8. How confident a which best repre			al support? Plea	se circle the number		
1	2	3	4	5		
I am not at all				l am very		
confident in				confident in		
delivering	delivering delivering					
psychosocial psychosocial						
support to				support to		
children and children and				children and		
families				families		
you have not been in	volved in provi		l support, pleas	e tell us the reason(s)		
		Training				
9. Have you ever h	ad any specific	training to provi	de psychosocial	support?		
YES	NO [

If YES please give details below (name of course, whether accredited). If possible please detail the name of the course, cost of the training course, whether accredited and approximate dates when you did the course.
Course name:
Accreditation:
Provider details:
Cost (if known):
Date attended/completed:
Contact Details
10. If we require any further clarification about any of your responses, are you happy to be contacted by the research team?
YES
NO
NO If YES please fill in the following details:
If YES please fill in the following details:
If YES please fill in the following details: Name