Thank you for visiting our questionnaire page.

Why are we doing this Dephi consensus?

Congenital heart disease (CHD) is one of the most common birth problems in infants, found in 9 out of every 1,000 babies born. We have shown poor growth in infants with CHD prior to surgery results in increased length of stay and post surgical morbidity.

The aim of these nutritional guidelines is to support the development of growth in infants (< 12 months age) with congenital heart disease (CHD) prior to surgery. The draft guidelines have been developed by the Paediatric Cardiology Dietetic/SLT team at University Hospital Southampton NHS Foundation Trust (UHS), with support from the British Dietitian Association Paediatric Cardiac Interest Group. This questionnaire forms part of a Delphi consensus which we want to ask you as experts about.

What happens next?

As experts taking part in this Delphi study you will be asked whether you agree or disagree with a set of statements regarding nutrition support in infants with CHD. There will also be an opportunity to provide comments as to whether you feel there is anything missing from each section. The study is anonymous to make sure everyone has an equal say. This Delphi study will be completed in 2 rounds using an on-line survey, with a final face to face meeting involving the British Dietitian Association Paediatric Cardiac Interest Group at UHS to validate the guidelines.

To be involved, simply complete this online questionnaire. It should take no longer than 5 - 10 minutes. It is entirely optional. If you do not wish to take part simply close the questionnaire. However we are really grateful for your opinions. There are no specific benefits to you from taking part but no risks either. All information you provide will be anonymous and cannot be withdrawn once you submit it. By completing the questionnaire you agree to participate in this process.

Section 1. Step 1 - Assess & classify nutrition risk

The aim of these nutritional guidelines is to support the development of feeding skills and growth in infants (< 12 months age) with congenital heart disease (CHD) prior to surgery. There are five steps within the nutrition guidelines and these questions will go through each section in sequence.

Using the scale from strongly disagree to strongly agree, please indicate the extent to which you agree or disagree with the following statements or questions.

If you have any additional comments to add please use the comments box at the end of each section.

Step 1 - the nutritional needs of infants with CHD will depend on the type of cardiac lesion

Step 1: Assess & classify nutrition riskÂ

All levels of health care professionals would be able to use these guidelines?

 Strongly disagree
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 Strongly agree

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The nutritional needs of infants with CHD will depend on the type of cardiac lesions?

 Strongly disagree
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 Strongly agree

 Image: Complex strength of the str

It is important to develop some nutrition guidelines for infants with CHD to improve growth before surgery?

 Strongly disagree
 1
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 10
 Strongly agree

 Image: Image of the strong stro

Infants with these cardiac lesions will have a lower nutrition risk

Stongly disagre	e 1	2	3	4	5	6	7	8	9	10	Strongly agree
Patent ductus arteriosus – (if early surger) 🔿	0	0	0	0	0	0	0	0	0	
Atrial septal defect	\circ	0	0	0	0	0	0	0	0	0	
Cor triatriatum	\circ	0	0	0	0	0	0	0	0	0	
Total anomalous pulmonary venous drainage	\circ	0	0	0	0	0	0	0	0	0	
Pulmonary stenosis	0	0	0	0	0	0	0	0	0	0	

Please write the \hat{A} names, if any, of CHD lesions you feel should be included in the lower nutrition risk list \hat{A}



Infants with these cardiac lesions will have a higher nutrition risk

Stongly disagree	1	2	3	4	5	6	7	8	9	10 Strongly agree
Coarctation of aorta	0	0	0	0	0	0	0	0	0	0
Pulmonary atresia	0	0	0	0	0	0	0	0	0	\circ
Tetralogy of Fallot	0	0	0	0	0	0	0	0	0	\circ
Atrial septal defect – (severe lesion)	0	0	0	0	0	0	0	0	0	\circ
Transposition of great arteries	0	0	0	0	0	0	0	0	0	\circ
Ventricular septal defect – (moderate to large)	\bigcirc	0	0	0	0	0	0	0	0	\circ
Arterioventricular septal defect	0	0	0	0	0	0	0	0	0	\circ
Hypoplastic left heart syndrome	0	0	0	0	0	0	0	0	0	\circ
Truncus arteriosus	0	0	0	0	0	0	0	0	0	\circ
Aorto pulmonary window	0	0	0	0	0	0	0	0	0	\circ
Patent ductus arteriosus (large/delayed surgery)	0	0	0	0	0	0	0	0	0	\circ
Tricuspid atresia	0	0	0	0	0	0	0	0	0	\circ
Ebstein Anomaly	0	0	0	0	0	0	0	0	0	\circ
Double outlet right ventricle	0	0	0	0	0	0	0	0	0	\circ
Partial anomalous pulmonary venous drainage	$^{\circ}$	$^{\circ}$	$^{\circ}$	0	0	\circ	$^{\circ}$	0	0	0

Please write the \hat{A} names, if any, of CHD lesions you feel should be \hat{A} included in the higher nutrition risk list \hat{A}



Infants with more than 1 cardiac lesion AND a congenital or chromosomal abnormality will have a higher nutrition risk

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
T21/18/13	0	0	0	0	0	0	0	0	0	0	
VACTRL/ CHARGE	0	0	0	0	0	0	0	0	0	0	
Gastrointestinal atresia	0	0	0	0	0	0	0	0	0	0	
Di-George Syndrome	0	0	0	0	0	0	0	0	0	0	
Congenital chylothorax	0	0	0	0	0	0	0	0	0	0	

Please write the names, if any, of congenital abnormalities and CHD lesions you feel should be included in the higher nutrition risk list



A cardiac lesion can be used to classify nutrition risk?

 Strongly disagree
 1
 2
 3
 4
 5
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 10
 Strongly agree

 Image: Image of the strong stro

Comments



Section 2. Step 2 - Assess & classify growth

Regular assessment of growth in an infant with CHD identifies early growth failure providing the opportunity to intervene

Regular assessment of growth in an infant with CHD identifies early growth failure providing an opportunity to intervene?



An infant with lower nutrition risk will be

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Gaining an adequate amount of weight e.g. 10 g/kg/day	0	0	0	0	0	0	0	0	0	0	
Weight not more than 2 centiles below birth centile after 3 weeks of age	0	0	0	0	0	0	0	0	0	0	

An infant with higher nutrition risk will be

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Not gaining adequate amounts of weight e.g.	\circ	\circ	\circ	\circ	0	\circ	\circ	0	\circ	\circ	
Sustained weight drop of 2 centiles or more from birth after 3 weeks of age	0	0	0	0	0	0	0	0	0	0	
Flattening of growth curve	\circ										
Growth curve dropping downwards or losing weight	0	0	0	0	0	0	0	0	0	0	

Comments



Section 3. Section 3 - Eating & drinking

Prevent oral aversion by referring and involving a SLT early to assess feeding skills

To prevent oral aversion a \hat{A} speech and language therapist (SLT) should review \hat{A} those with high nutrition risk \hat{A}



$An\hat{A}$ infant should have a SLT review if they

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Shows signs of distress during or after a feed	0	0	0	0	0	0	0	0	0	0	
Breathing sounds are noisy/ wet during/after a feed	0	0	0	0	0	0	0	0	0	0	
Coughing, gagging or choking episodes	\circ										
Losing fluid from the mouth or fluid/ food remaining in the mouth	0	0	0	0	0	0	0	0	0	0	
Changes in breathing/ saturation levels during a feed	0	0	0	0	0	0	0	0	0	0	
An infant changes colour during or after a feed	0	0	0	0	0	0	0	0	0	0	
Regression of oral feeding skills or oro- motor difficulties	0	0	0	0	0	0	0	0	0	0	
Difficulty in moving from enteral feeds to oral intake	0	0	0	0	0	0	0	0	0	0	
Breath holding during a feed	\circ	0									

Comments

-		

Section 4. Step 4 - What & how much is eaten/ drunk?

Restricted feed or food intake may impact on the infant's ability to maintain adequate nutritional status

Infants with a lower nutrition risk will

Strong	y disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Not vomit		0	0	0	0	0	0	0	0	0	0	
Drink 150ml/kg or above		0	0	0	0	0	0	0	0	0	0	
Keen to drink		0	0	0	0	0	0	0	0	0	0	
Finishes expected amount of	infant feed	0	0	0	0	0	0	0	0	0	0	
Breastfeeds for expected dura	ation	0	0	0	0	0	0	0	0	0	0	

Infants with higher nutrition risk will.....

Stro	ngly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Vomit with most feeds		0	0	0	0	0	0	0	0	0	0	
Be fluid restricted or drink		0	0	0	0	0	0	0	0	0	0	
Only drinks a portion of th	e feed offered	0	0	0	0	0	0	0	0	0	0	
Require a nasogastric tube		0	0	0	0	0	0	0	0	0	0	

Comments



Section 5. Step 5 - Nutrition Care plans - A, B or C

Nutrition care plan A - Infants in this group will be

Strongly disagree	1	2	3	4	5	6	7	8	9	10 Strongly agree
Growing well	0	0	0	0	0	0	0	0	0	0
Be keen to drink	0	0	0	0	0	0	0	0	0	0
A CHD lesion with a lower nutritional risk	0	0	0	0	0	0	0	0	0	0
Will require between 90 - 100 kcal/kg	0	0	0	0	0	0	0	0	0	0
Require 1.5 g/kg protein (e.g. 2g protein per 150ml)	0	0	0	0	0	0	0	0	0	0
Should have breastmilk or standard infant formula	0	0	0	0	0	0	0	0	0	0
Weaning foods from 17 – 26 wks age	0	0	0	0	0	0	0	0	0	0
Should be reviewed by local team	0	0	0	0	0	0	0	0	0	0

Comments



Nutrition care plan B - Infants in this group will be

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Not growing well	\circ										
Do not always finish feeds offered	\circ										
CHD lesion with a higher nutritional risk	\circ										
Shows signs of distress during feeds	\circ										
Fluid intake	\circ										
Will require between 110 - 120kcal/kg	\circ										

Will require 2.5g/kg protein	0	0	0	0	0	0	0	0	0	\circ
Should have breastmilk/ infant formula & 30 - 50% energy/nutrient dense formula	0	0	0	0	0	0	0	0	0	\circ
1 tsp nut butter in weaning foods from 17 - 26 wks of age	0	0	0	0	0	0	0	0	0	\circ
Dietetic/ growth review every 2 weeks	0	0	0	0	0	0	$^{\circ}$	0	0	\circ

Comments



Nutrition care plan C - Infants in this group will be

Strongly disagree	1	2	3	4	5	6	7	8	9	10 Strongly agree
Losing weight/not growing well	0	\circ	0	0	0	0	0	0	0	0
CHD lesion with higher nutrition risk	\circ	0	\circ	\circ	\circ	0	\circ	0	\circ	0
Takes a long time to feed or tires easily	\circ	0	\circ	\circ	\circ	0	\circ	0	\circ	0
Has difficulty feeding	0	\circ	0	0	0	0	0	0	0	0
Fluid restricted	0	\circ	0	0	0	0	0	0	0	0
Will require 120 - 150kcal/kg	0	0	0	0	0	0	0	0	0	0
Will require up to 4g/kg protein	0	\circ	0	0	0	0	0	0	0	0
Breastmilk/ infant formula & 50 - 80% energy/ nutrient dense feed	0	0	0	0	0	0	0	0	0	0
1 - 2 tsp nut butter in weaning foods from 17 - 26 weeks	0	0	0	0	0	0	0	0	0	0
Dietetic/ growth review every week	0	\circ	0	\circ	\circ	\circ	\circ	\circ	\circ	0

Comments



Infants will no longer require intensive nutrition support when

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
They have achieved catch up growth to 1 centile below birth weight	0	0	0	0	0	0	0	0	0	0	
They are 12 weeks post definitive surgery	\circ	0	\circ	\circ							

Comments



Section 6. Participant characteristics

What is your gender?

- O Male
- O Female
- O Prefer not to say

About you



What is your professional background?

Specialist											
Paediatric			Consultant	Consultant					Health	Community	
Nurse	Registrar	SHO	Cardiology	other	SLT	Dietitian	OT	Physio	visitor	nurse	Other

How long have you been working with infants with CHD?

< 2 years 2 - 4 years 5 - 6 years 7 - 8 years 9 - 10 years > 10 years

How would you describe your place of work?



Please provide an email address to allow us to send your individual summary



Thank you for taking time to complete this questionnaire.