

Caring for my child every day at home.

Parents frequently need practical help and support to care for their children with complex healthcare needs and disabilities at home.

Is this an aspect of your child's care that you want to change or improve?
If yes, please provide a brief description of your current situation

YES. MORE CARE IN THE HOME AS WE HAVE NONE AT THIS TIME

Do you have a 'key worker' to coordinate care? Circle Yes ☒ No Don't know
If yes, please describe (e.g. their name, their job title, what they do)

What works well at the moment with your child's everyday care?

WE CAN ACCESS CHIC NURSE DANIVA NURSE IN HOSPITAL & DR VERY WELL

What would you like to work better at the moment with your child's everyday care?

~~HELP~~ HELP DAY TO DAY IS NEEDED IN THE HOUSE

How important is it to change/improve this aspect of your child's care?
Circle one option

High priority

Medium priority

Low priority

Follow-up appointments and routine tests

Children with complex healthcare needs and disabilities frequently attend follow-up appointments and need routine tests (such as blood tests).

Is this an aspect of your child's care that you want to change or improve?
If yes, please provide a brief description of your current situation

US appointments in [redacted] are on different days these need to be on same day to save on travel.
AND Afternoon appointments to give us time to get there

What works well at the moment with your child's follow-up appointments and routine tests?

[redacted] hospital is better for us but not all care is available in there

What would you like to work better at the moment with your child's follow-up appointments and routine tests?

Blood test at home & always afternoon appointments.

How important is it to change/improve this aspect of your child's care?
Circle one option

High priority

Medium priority

Low priority

My overall aim would be to ...

HAVE
wish

CARE

UNDER

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about

Use this rating scale to show where you are now:

1. Very far from my / our aim 2. 3. 4. 5. 6. 7. 8. 9. 10. I have achieved my / our aim

Things I / we want to change / improve now.	How I / we want things to be	Care options and service provision my / our child / family need to get there?	Where is the best place for my / our child to be cared for in each situation / scenario	Potential impacts / changes in my / our child's current situation over
Nursing care when [redacted] is very sick so he is able to stay home & a nurse to come to him	in an ideal world all care tests etc in the home	This is being looked at for us & discussions with Dr & clinic nurse	in our own home he is very uncomfortable in hospital	

Planning ahead. As like to do with my child and family now or in the future

What would be your overall aim in changing or improving the activities that you do with your child and family now or plan to do in the future?

My overall aim would be to ...

Use this rating scale to show where you are now:

1. 2. 3. 4. 5. 6. 7. 8. 9. 10.
Very far from my / our aim I have achieved my / our aim

Things I / we want to change / improve now.	How I / we want things to be	Care options and service provision my / our child / family need to get there?	Potential impact of changes in my / our child's condition / situation over time?
we would like more disabled activities	with all of [redacted] needs a helper in the home	we need oxygen whenever we go soft cushions	
on the Island so that we could reach them easily.		wheel chair + medication so another pair of hands	
we would like to improve how we travel with [redacted]		with [redacted]	