

#ThisIsMe



My child has a hidden health need that can't be seen. We are warriors and gain strength from supporting each other but might need you to be part of #TeamHiddenHealth

Checklist for parent/carers – Ask, Ask Ask!

- Practise and write down questions before your appointments so that you can get the answers you need
- Ask to speak with your doctor separately to your child/young person to speak through your worries
- Ask if there is a hospital play specialist, youth worker or family support team that can help with appointments or treatment times or can act as a “second ear” to listen to information (e.g. reasonable adjustment from the Equalities Act 2010)
- Ask if there is a hospital or clinic quiet time / quiet room or sensory room that can be used to support your child's needs
- Ask, follow up, question, ask again and be assertive
- Ask for support to have all information and communication in an accessible way as part of NHS Accessible Information Standard legislation <https://www.england.nhs.uk/ourwork/accessibleinfo/>
- Find training or online learning to improve your understanding knowledge about #HiddenHealth needs
- Get help from support groups like your local Parent Carer Forum (www.nnpcf.org.uk) on how to ask for what support and assistance is needed
- Ask for a list of local groups or online links for services that support families locally your “local offer for SEND”
- Share a top tip or success story with another parent to keep everyone people feeling “anything is possible”
- Find our a national charity / support group that offers information, advice and guidance on your child's medical needs/ condition

Notes

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Our top links and tips:

- ✓ Find your local parent carer forum
<http://www.nnpcf.org.uk/about-the-nnpcf/find-your-local-forum/>
- ✓ Contact - Supporting families with advice and guidance on long term conditions and disability support
<https://contact.org.uk/>
- ✓ Council for Disabled Children is UK wide with lots of resources about SEND support for education and health
<https://www.ncb.org.uk/about-us/our-specialist-networks/council-disabled-children>
- ✓ Support to challenge school support for SEND
<https://www.ipsea.org.uk>
- ✓ Free online disability awareness training to share with others
<https://www.disabilitymatters.org.uk>
- ✓ Local (UK wide) charity set up by a young person with Lupus to raise awareness in schools of hidden disabilities
<https://raiise.co.uk>
- ✓ NICE transition guidelines
<https://www.nice.org.uk/guidance/ng43>
- ✓ Transition resources and examples
<https://www.rcpch.ac.uk/resources/transition-adult-services>
- ✓ Free financial support and access to grants for families
<https://www.turn2us.org.uk/>

**Download and share for free from:
www.rcpch.ac.uk/hiddenhealth**

Created by parents and carers from Alder Hey with RCPCH &Us