

**#ThisIsMe**



**#HiddenHealth**



## The toolkit includes:

- Explanation of the project
- Poster for your local area
- **#HiddenHealth #ThisIsMe** cards
- Examples from parents of good practice support they have had to inspire your services
- Checklists for workers & parents/carers to support **#HiddenHealth** needs
- **#HiddenHealth** goodies

Download and share for free from:  
[www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth)

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

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# #HiddenHealth



Throughout 2018/19, parents from Alder Hey Children's Hospital have been working with RCPCH &Us to develop a project on hidden health. The project has been thinking about three different elements of being "hidden"

- Children and young people with a hidden condition or illness
- Hidden family carers providing support
- Hidden support services such as parent carer forums that are not always signposted by staff.

Project members have shared their hopes and wishes, collected the experiences of others and looked at what would help them and their children to feel visible again. Project members said that hidden health to them means:

*"Something that makes me a warrior, where I need notes sharing between departments, links to be made between symptoms, where I gain strength and empowerment through supporting my child with a hidden health issue" (Liverpool 2018)*

*"Conditions that the world and people just don't understand - mental health, blood disorders, autism, bowel issues, breathing issues (no tubes or gadgets to see), something that isn't relatable to you" (Liverpool 2018)*

*"Something you can't see. We need you to be tolerant and understanding" (Liverpool 2018)*

Over 150 parents, carers and professionals have supported the development of this toolkit through being part of the project team, taking part in consultations or being part of the toolkit testing in roadshows.

The **orange** resources are for parents/carers to use. The **blue** resources are for workers. You will get a copy of both in your toolkit so that you can see what each other has and also for you to pass on.

The cards also come in two varieties; **blue** is to be able to give to someone quickly that just explains basic information about #HiddenHealth needs. **Orange** cards allow you to write some personal information on them about the condition, what support is needed or not using words like "injection / bloods" as this can lead to a meltdown - you write what is useful to you and what you are happy to share. Then use the cards with people that can help like receptionists, other departments, shopping centres - you choose!

You can read more about the project at [www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth)

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## Local support available

Please download the poster and add in details for your:

- local parent carer forum (listed at [www.nnpccf.org.uk](http://www.nnpccf.org.uk)),
- your local advocacy service e.g. PALS, Healthwatch and
- how people can access play specialists, youth workers, disability nurses and other staff who can support parents with support, distraction techniques or advise on sensory rooms or other available reasonable adjustments.

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**#HiddenHealth**

**Do you need support with #HiddenHealth needs?**

- Children and young people with a hidden condition or illness visiting health services
- Support for hidden family carers
- Access to support services to support #HiddenHealth

Your local parent carer forum is...

Download free #HiddenHealth resources from [www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth)

Your local advocacy service is:

Your local play/youth/disability nurses or team are...

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Alder Hey Children's **NHS** Foundation Trust

**RCPCH &Us**  
The voice of children, young people and families  
[www.rcpch.ac.uk/and\\_us](http://www.rcpch.ac.uk/and_us)

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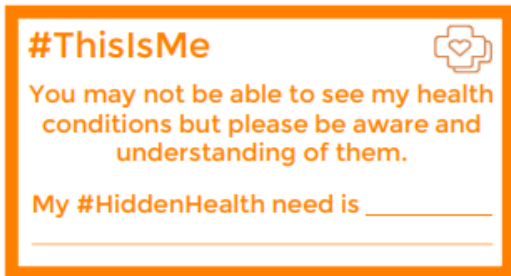
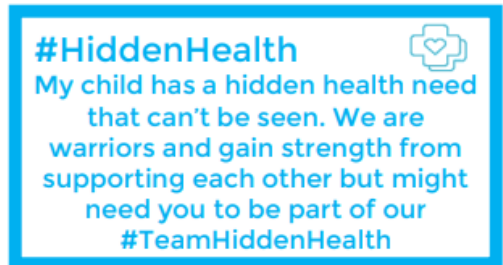


# #HiddenHealth



You can download **#HiddenHealth** or **#ThisIsMe** cards for free from [www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth)

**#HiddenHealth** cards are quick cards to leave with someone to make them aware of Hidden Health needs, conditions or illnesses. They are generic and could be shared when you use a disabled toilet without a visible disability, have a child having a meltdown or at other times where you want to raise awareness without a long conversation.



**#ThisIsMe** cards are personalised cards with space to note down the Hidden Health needs and specific help that might be needed. Examples like “do not mention the word needle” or “my child will only respond by pointing” will help in appointments and visits to health services.

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**We asked parent/carers, children & young people to share their examples of when there has been good support for their #HiddenHealth. They said:**

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"We liked it when the Doctor wrote to both of us and included information about school, activities we had talked about and used simple language about the treatment options"

”

Parent - RCPCH &Us

“

"One Doctor helped us by telling the other clinics about how best to talk to my child, giving them something to hold & not looking directly at them - this meant that I didn't have to explain it all"

”

Parent - RCPCH &Us

“

"It helped when the Doctors worked it out for me to see everyone together, it made me less nervous about moving to adult's services knowing we had already met up a few times"

”

Young Person- RCPCH &Us

“

"We have a quick access card for A&E and the phone number for the specialist so we can call for advice, no matter where we are - even when on holiday which helps us to feel reassured "

”

Parent - RCPCH &Us

“

"I don't like having blood tests so the Doctor arrange for the play lady to come with me and we made models out of lego so I didn't notice and didn't get upset like before"

”

Child- RCPCH &Us

“

"Having people know and understand the legislation about education health care plans and reasonable adjustments really helps, it means the Doctors can help get support right at school"

”

Parent - RCPCH &Us

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The checklists can be downloaded for healthcare professionals on **#HiddenHealth** needs and for parents/carers to be empowered on sharing **#ThisIsMe** information. You can download and share for free from [www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth)

**#HiddenHealth**

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 workers - Stop, Listen, Think, Look**

- Read as much as you can in the notes before they arrive and start with a recap from your point of view. Have a few good questions to ask families when they arrive to build rapport and understanding about the #HiddenHealth need
- Remember every family & every #HiddenHealth need is different and what our different support
- Practise talking in a positive way. Children can go on to achieve challenges are
- Have a list of specialists
- Have a list of local groups for guidance
- Forum ([www.nnpcf.org.uk](http://www.nnpcf.org.uk))
- Be proactive in pulling together help to be my child/young person
- Find training or courses about #HiddenHealth
- Update your training for people and businesses
- Know about your health and fitness (2014)
- Think about BSL other communication Accessible <https://www.rcpch.ac.uk/hiddenhealth>

Your top tip

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**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 child/young person to speak through
- Ask if there is a family support team that can help as a "second ear"

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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://raise.co.uk>
- NICE transition guidelines <https://www.nice.org.uk/guidance/ng63>
- 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/>

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**Checklist for our patients and families:**

- Could the #HiddenHealth need affect this appointment? What do we do to help?
- Are there any other conditions, disabilities, worries or concerns you have your child got a health passport or emergency treatment card? If not, would you like an basic summary to share with others about the #HiddenHealth need?
- Would it be a good time for your child and the family to start talking about the #HiddenHealth need? (share transition approach, link to adult services?)
- What else I could do to help with your #HiddenHealth needs?
- What national or local group that offers information, advice and guidance on #HiddenHealth needs affect your day?
- How can you notify your school about support that is needed to help your child?
- How can you contact your local Patient Advice and Liaison Service (PALS) for help, support and advice?
- How can you contact your local #HiddenHealth #ThisIsMe cards?

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## Notes

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We need YOU to help share the #HiddenHealth resources with parents/carers, doctors, nurses, healthcare professionals, schools, support staff and everyone!



**Royal College of  
Paediatrics and Child Health**

*Leading the way in Children's Health*

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