

# Stroke in childhood

## Questions to ask...

**when looking for therapy services or attending therapy appointments**

Finding the right therapy can be a challenge, and you may find you do not know what to ask when looking for it and during appointments.

**'Therapy'** may include physiotherapy, occupational therapy, speech and language therapy and psychology

- Physiotherapists help with movement and mobility
- Occupational therapists help with doing everyday things - getting dressed, getting washed, writing, typing, and playing. They look in detail at how you use your arms and hands
- Speech and Language Therapists help with communication and eating and drinking (swallowing and feeding)
- Psychologists help with thinking, feelings and learning

Here are some questions that parents and young people may find helpful. These questions may also be useful when finding out about private therapy options. They may not all be relevant to your family, but you may find many of them useful.

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## Knowledge and experience

**What is your (or your team's) experience in:**

- working with children and young people affected by stroke/brain injury
- working with children with movement difficulties like hemiplegia
- working with children with behaviour/emotional support needs



## Delivery of therapy

- What types of therapy do you offer children with similar health needs?
- Is therapy offered one-to-one, or in groups, or both? What are the benefits of each?
- Where is therapy offered: at home, in clinic, in the community, in school?
- If your team don't go into schools, are there other therapy services in our area that work in school settings?
- Will you be able to offer training to staff who support our child in other settings (for example childminders, teachers) so they can carry out therapy programmes and support our child in the right way?
- How long will our child be able to be seen by your service, and offered therapy?
- Do you offer ongoing review as children grow/move up to secondary school?
- If you do not offer regular review, how do we re-access your service and what waiting times can we expect?
- Does therapy need any special equipment (for example splints, toys, computer programmes), and how do we get this?
- How often is therapy (every day for a set period, every week for a set period, monthly) and how long is each appointment? Are we likely to see the same therapist?
- If therapy needs to be intensive (daily) to achieve the best results, how can your team support this (for example, delivering sessions, training others, reviewing how therapy is going, assessment before and after)?
- How will our family be included in therapy delivery? Can we include parents, grandparents, brothers and sisters?
- If tiredness or another medical condition affect our child's ability to participate in the amount or intensity of a therapy programme, how can we manage this?
- Will we see the same therapist for assessment and for therapy?



## Effectiveness of therapy

- What kind of assessments will you use to identify how my child is doing at the beginning of therapy, and review progress?
- What kind of changes can we expect to see in day-to-day life? Should we identify some specific things we can monitor for change (for example getting dressed, eating, schoolwork)?
- What kind of goals can we set together with you to measure how therapy is making a difference? How can we involve our child in this process?
- How can we encourage our child to participate in therapy? How can we make therapy fun?
- If a particular therapy approach is not working for our child, how do we identify the best time to stop and try something different?
- If we would like to adjust the timing of therapy to fit in with our child's/our family's needs, how can we do this?
- Can we have a written version / handout of therapy exercises to do at home, or can we record how to do them on a phone/tablet etc?



## Communication

- What kind of reports can we expect from your team to update us on progress?
- Are reports shared with other professionals involved in our child's care (GP, educational professionals, private therapists etc)?
- How often will we be able to talk through how things are going?
- How can we best communicate between appointments (phone, email, Skype)?
- Will you be able to attend meetings to talk about our child's therapy and support needs, for example in nursery or school settings?
- If you are not able to go into school, can you give us some written notes or therapy programmes to share with them?
- We are seeing a number of therapists – how will they communicate with one another – and will there be a combined approach to communicating with us?
- Will you make recommendations about what is needed in the future for our child to best support their development?



## Transition

- Our child is approaching the age when they will start to see adult services (for medical and therapy care). How does this change happen and how is information shared?



## Other services

- Are there other services linked to your team that would be helpful for our family (for example hydrotherapy, equipment services)?
- Are there other services in our area (not necessarily therapy services) that you know other families have benefited from (for example leisure, sporting, social activities, parent or young person support groups)?
- Are there specialist services outside our area that would be helpful for our family, such as advice or therapy?





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