

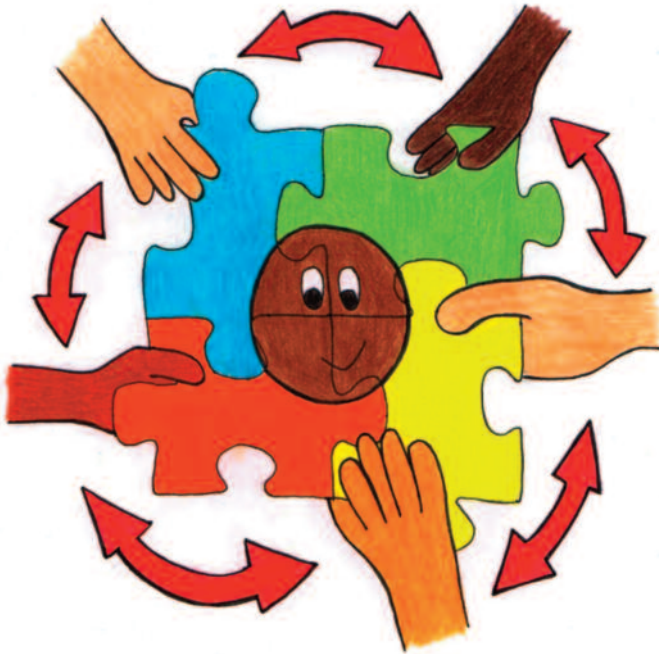


Division of
Clinical Psychology

Faculty for Children, Young People
& their Families

Children and young people with physical health needs

How psychological services
contribute to the care pathway



Why include psychological services when people are dealing with physical health issues?

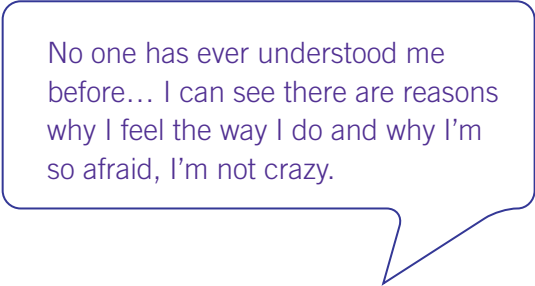
Children and young people with health conditions, and their families, are four times more likely to experience significant anxiety, low mood and psychological distress than their healthy peers. Given the often arduous treatment and at times life threatening conditions, children and parents can understandably experience anxiety, low mood and symptoms of PTSD. Good psychological services can help at every step of the journey – at diagnosis, during treatment and beyond.

Good psychological services should be available to help:

- the child or young person;
- parents or carers;
- the wider family network; and
- the professional care team.

When a diagnosis is first received, psychological input can help young people and their carers to make sense of their condition and feel as if they have some measure of control over what is happening to them. People often find it helpful to communicate about their condition and how it makes them feel. This is vital as they begin treatment.

Psychologists also play a key role in researching the psychological impact of treatment and how this can be minimised, making sure the services provided are the best quality possible.



No one has ever understood me before... I can see there are reasons why I feel the way I do and why I'm so afraid, I'm not crazy.



'Jason' is a three-year-old boy who was attacked by a guard dog on his grandparents' farm. His grandmother managed to get the dog away from him, but Jason had extensive and serious bite injuries to both legs and arms and needed skin grafts. Jason needed to stay in hospital for at least three weeks. The role for psychology was initially to provide information for all concerned, including the treating team, about what should be expected as a 'normal' reaction to trauma for a three-year-old child, and also to consider the trauma to his grandmother.

Further work was planned to meet with the family to facilitate the adults to express guilt, anger, and anxieties about what had happened, and to address how to repair and restore their previously good relationships. Information about building an account of the incident that is honest and age-appropriate was provided for Jason, which could be developed over time as his understanding progressed.

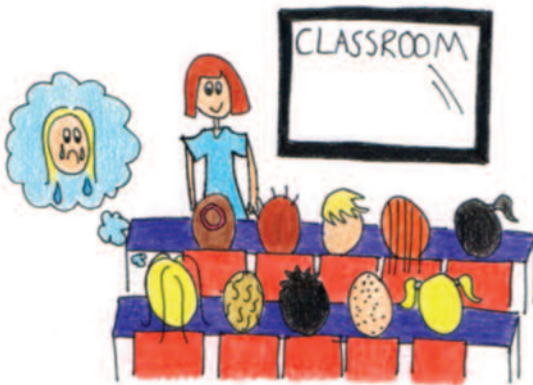
Individual work with Jason was arranged to help him to cope with the immediate emotional impact of his scars. This work took three sessions, with feedback from staff that the boy and family were more settled and ward staff found it easier to give treatment and so were less stressed.

Psychological input during treatment

During hospitalisation, some children and young people become acutely distressed, anxious or low, or exhibit some changes in their behaviour or have difficulty adhering to treatment. Good psychological input can help them to manage their feelings and cope with the demands of their condition or treatment.

Once children are back at home or back at school, misunderstanding of behaviour by carers, teachers and other people can lead to difficulties with relationships and affect the child or young person's self-esteem. Psychological input can help everyone around the person to develop a better understanding of their behaviour as a normal response to their condition and treatment. A positive experience of treatment and care is an important health outcome in these circumstances, and good communication between professionals, young people and their families is key to achieving this.

A well-coordinated care pathway reduces worry and makes it more likely that the treatment will be followed through all the way. Psychological input can also help children and young people move to different phases of treatment. For instance, moving from children's to adult services means that the young person may need to manage all the aspects of treatment themselves without their parents. This can be daunting and complex, on top of all the other things that go with growing up, and psychological input can make a big difference to how successfully these transitions are navigated.





'Paula', aged 15, has leukaemia; her parents are divorced and argue constantly. Paula's 13-year-old sister has started to self-harm. Paula won't get out of the car at the hospital, refusing chemotherapy. The oncologist wants to sedate her and is talking to legal services. A referral is made to the clinical psychology service to assess the situation, provide a holistic formulation and make recommendations about interventions. A treatment package is designed which can both assist the treating team with their care plan and also support the family to improve their communication and relationships, develop parenting strategies to keep the girls safe, provide positive coping strategies for managing procedural distress, and help Paula to explore her feelings and choices.

Now I understand my child's memory problems and how to help him. I don't blame him or myself for some of his behaviour; it's to do with brain injury... he still needs boundaries though.

Psychological input after treatment

Once treatment is complete, children, young people and their families may still need psychological input. Some may need practical support to work out a plan for moving back into school or further study.

Sadly, despite ever-increasing success with treatments, some may need to plan long-term care, or may be facing death and bereavement.

In addition, one-third of children (and their parents) admitted to paediatric intensive care have symptoms of post-traumatic stress disorder and one in ten subsequently struggle significantly with this issue. Skilled psychology practitioners, such as clinical psychologists, can be there to support people through these distressed and anguished times.

Some people's lives are long novels.
My child's life is a short story with
just as much meaning





'Alice', aged 13, has idiopathic chronic pain syndrome, frequently attends her GP, paediatrician and local A&E. There is no medical treatment for her disability. She has stopped going to school, has limited mobility, disrupted sleep, panic attacks and low mood. Her mother has given up work to look after her and the whole family has adapted to her disability. The intervention helped Alice learn psychological methods to tolerate her pain, and recognise psychosocial triggers which intensified her pain experience. Anxiety management and self-hypnosis resulted in better sleep, and liaising with her school facilitated her return, initially on a part-time basis.



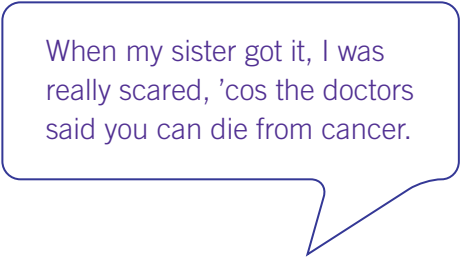
My daughter has always been a bit shy and awkward, and a bit of a worrier, so I was worried when my grandson became ill that she wouldn't cope. It's good she has support too.

Psychological input for the wider care circle

While psychological input is crucial for the child or young person facing physical health issues, it also has an important role to play in their wider circle. All members of the care team can benefit from the insights that a psychology practitioner, such as a clinical psychologist, brings in terms of understanding the feelings and reactions of the child or young person and their family. Well-supported staff, who have access to consultation and training from clinical psychologists in how best to promote adjustment and psychological wellbeing and recognise signs of psychological distress, deliver better quality patient-centred care and are better able to do their jobs with care and compassion. Clinical psychologists are also well placed to provide quality assurance and governance, and can support the whole system in complex decision-making.

Members of the family, parents and siblings, should also be given an opportunity to develop ways of managing their worries and complicated emotions, and communicate about how they are feeling. At times this may be the focus of the intervention, rather than working with the unwell child.

There are many benefits of psychological input for children and young people with physical health conditions, and their families. So it is important that services are made available as widely as possible, and that people are helped to understand that there is no stigma attached to asking for help.



When my sister got it, I was really scared, 'cos the doctors said you can die from cancer.

These are the features you should expect in a psychological service which supports children and young people with physical needs

- The psychology service is easily accessible, available locally and at appropriate times.
- The service is integrated within the paediatric service.
- The service is patient-centred with clear values and principles, focusing on a whole child and family approach.
- Young people and families are involved in planning their care and developing the service.
- The service embraces diversity and works to avoid stigma.
- The service encourages good lines of communication between professionals and families, and other agencies and teams.
- The service is concerned with longer term psychological wellbeing (like self-esteem and relationships) rather than only the immediate issues.
- The service helps people to be resilient and adjust to circumstances, rather than just focusing on vulnerability.
- There are clear arrangements for moving from children and young people's services to adult services when necessary.
- Feedback from people who are using the service is part of how the service is evaluated.

If you feel that the information in this leaflet applies to you or someone you know, you can find out more from:

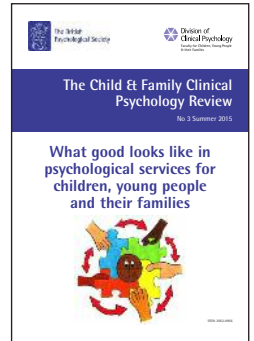
Paediatric Psychology Network: www.bps.org.uk/cypf

MindEd: www.minded.org.uk

This leaflet summarises a chapter in *What good looks like in psychological services for children, young people and their families*.

Hard copies can be requested for free from Helen Barnett, British Psychological Society: Helen.Barnett@bps.org.uk

Electronic copies can be downloaded for free from:
<http://shop.bps.org.uk/publications/child-and-family-clinical-psychology-review-no-3-summer-2015.html> or by scanning the code below.



If you would like to discuss any of the information in this leaflet further, please contact: dcpchildlead@bps.org.uk

