



Psychology services for families affected by CHD in Ireland provided by Heart Children Ireland

Suzanne Treacy
Dr. Deirdre O'Neill
Cologne
21st March 2013



Background

- In 2008 Heart Children Ireland funded a Cardiac Clinical Psychologist for 3 years in Our Ladys' Childrens' Hospital.
- In 2011 Heart Children Ireland was asked to continue the funding for another 3 years but in the uncertain economic climate it could not commit to that level of funding again.
- Despite excellent feedback from families the post disappeared.



- The hospital cardiac psychology service has always been highly valued but under-resourced.
- It has to prioritise in-patients and those preparing for/ distressed by hospital procedures.
- Heart Children Ireland were concerned about the much reduced service for families.

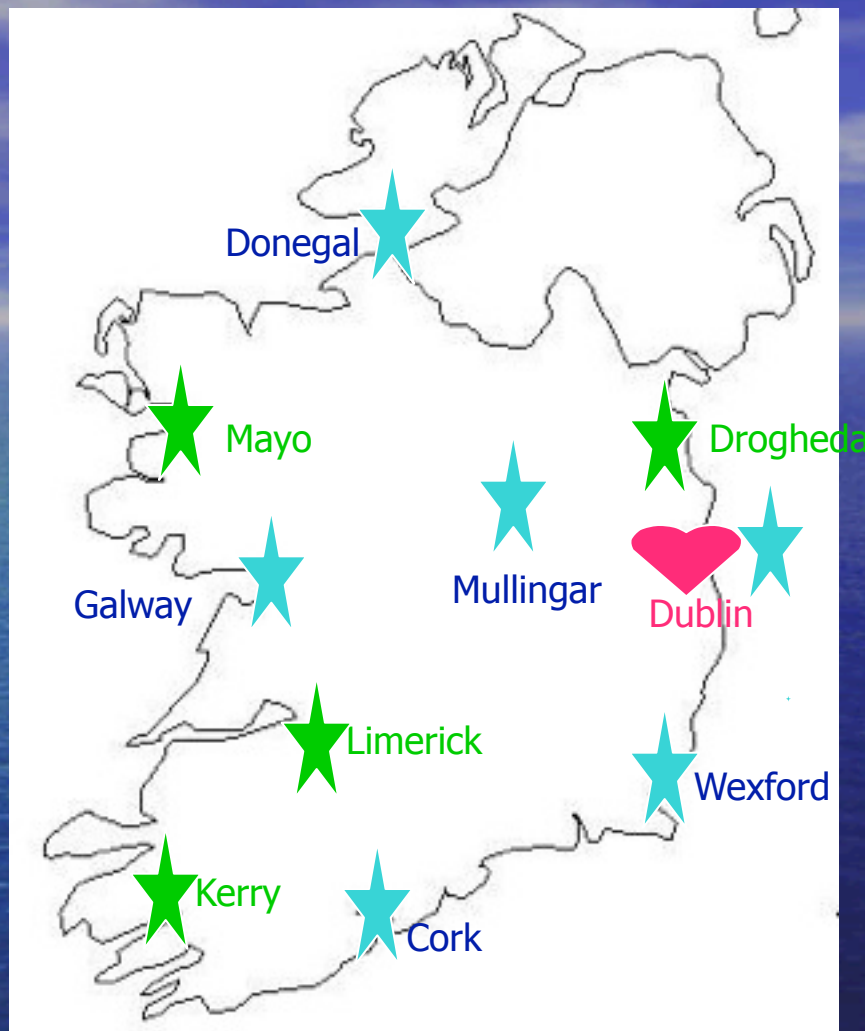


- Discussions began between Heart Children Ireland and Psychologist with cardiac experience to develop a tailor made service.
- As discussions were ongoing Heart Children Ireland received a donation of €116,000 from our corporate sponsor, Certus.
- As €40,000 of this amount was assigned to another project the decision was made to use the remainder for the Psychology service.



Family Support Service

- Family Support meetings – Parents/parents and young child/young adults/parents and siblings.
- Parenting Groups – 4 weekly group sessions for parents of children in primary school (aged 4 – 12).
- Countrywide meetings with parents and young adults with a presentation by the psychologist 'Supporting a child with a cardiac condition'.



- Meetings held in 2012



- Meetings planned for 2013



- location of National Pediatric Cardiac Centre



Subjects discussed at meetings

- Ongoing parental trauma associated with child's surgery.
- Impact of cardiac-related events on the parents' own relationship.
- Anxieties about balancing the needs of all the family members.



- Dealing with comments by members of the extended family, peers and strangers.
- Supporting the child to understand his/her condition and deal with its effects.
- Bureaucratic frustrations i.e waiting lists, health service inconsistencies, financial worries.



Benefits of Service

- Members can access this service on demand at a time that suits them and in the nearest town/city to them.
- The service is free and open to all members of the family.
- Service is cost effective.



- The service will develop and change to suit the needs of the membership, eg research, Lecture series.
- Childminders are provided at countrywide meetings.
- Lunch is provided.



Future Considerations

- Only members of Heart Children Ireland are in receipt of this service.
- Ongoing fund-raising to fund the service in the present economic climate is difficult.
- The psychology service in the hospital is still under resourced.



Feedback From Parents

'I have the tools to help (the children and her husband) get through days and nights. I have a life raft when I feel I am drowning in the weight of sickness, worry and fear'.

Comment from a parent attending the service during a period where the family had to deal with a number of unexpected, cardiac-related stressors a number of years post-diagnosis.



'Because of her history of feeding and then eating problems and the medical concerns about her weight, mealtimes had taken over our family life for a long time. We dreaded every meal. You (the psychologist) helped me understand what happened, how the habits developed. You helped me understand the reasons underneath the ideas you gave me too, that's why I relaxed and tried them. I didn't believe things could change so much so quickly. I know it sounds dramatic but this has changed our lives, I can't believe it'.

Example of a parent attending the service to address a specific, ongoing cardiac related issue.



'Thank you for a really useful, practical and insightful program'.

From a parent who attended a parenting group.



'I believe the psychology services are one of the most important aspects of the work undertaken by Heart Children Ireland. While the surgical team and machines play a vital role in keeping my sons alive, it is the work of the psychologist that make it possible for those lives to be lived well'.

This comment is from a mother who has two children with a congenital heart defect.