

Our Family Support Department



- Family Support Workers create good conditions for people to share how they are.
- They problem solve and direct people using their network of contacts, professional standards and expertise.
- How EB impacts on health and life is highly complex - family support workers deal with the whole system.



EB COMMUNITY CARE

Our Family Support Team (FST):

Offers a bespoke model of service *from birth, diagnosis and beyond.*

Supports families living in both the North and the South of Ireland

Offer home visits to families

Offer support calls to families

Are available over 5 days per week

Make avg 50 calls / visits per month

We currently fund EB outreach nurse working out of Children's Health Ireland, (CHI) at Crumlin

We meet monthly and quarterly with the team in CHI, believing good communication results in better services for families

Agreed funding for 2nd EB Outreach Nurse between CHI and St James's (SJH)

Collaborating with CHI and SJH to scope out role

Oversee all service-level agreement (SLA) input for DEBRA Ireland

Create clear pathway of communication for post holder



3 x Family Support Team = 2 FTE

Fund bespoke care packages for families

Provide Support to all stakeholders

Collaborate with Disability Federation Ireland (DFI) – setting up of national FST networking group

Offer and fund Supervision to EB nurses working with families in the community



FINANCE & SUPPORT

Oversee all funding and grant expenditure within the service.

We are patient led and respond to our families emerging needs

We have a number of different income streams available to families

Process AVG €60K-€70k per annum directly to families for their wellbeing

FAMILY EVENTS



Memorial service

Annual Family event

Peer support meetings

Collaborate with DEBRA UK to organise for families to attend peer events in UK



MANAGEMENT

To oversee all aspects of family support service

Ensure we have easy clear pathway for families to access our service

Continue to liaise with families to ensure we remain patient led

Record statistics to allow better analysis of service

Board meeting attendance

Strategic planning with Senior Management Team (SMT) and Board of Directors



PRINCIPALS OF OUR FAMILY SUPPORT SERVICE

- A professional service that aims to meet the needs of families living with EB.
- To establish a stabilizing support for families living with EB
- To understand that every family comes with their own set of complexities and to be able to meet families at that point.
- To help families integrate EB into their lives
- To understand grief and how it may present
- To understand trauma and in particular attachment trauma when a baby is born with complex needs
- To ensure we offer a consistent, fair service to all families living with EB
- To advocate for families living with EB both on a personal level and on a national level