

Support for young carers looking after someone with a palliative care diagnosis



What is the initiative?

FRESH – Friendship, Respect, Emotions, Support, Health

Who runs it?

St Michael's Hospice

Who does it benefit?

Young carers aged 14–19 in Herefordshire and the county borders who have a close adult family member with life-limiting illness and a palliative care diagnosis.

What does it do?

The young carer programme FRESH works to improve the life chances of young carers during the time of a palliative care diagnosis and bereavement. The multi-disciplinary healthcare team at St Michael's Hospice offers individual support, group work, whole family interventions, advocacy, peer mentoring, recreational activities and outreach. Community education for voluntary and statutory agencies to raise awareness and increase the identification of young carers with an adult family member receiving palliative care is also an important part of St Michael's Hospice strategy.

When did it start?

2010.

Why was it started?

St Michael's Hospice already had an established whole family programme, called the Saturday Club, for young carers aged 5–16 years. As this work became better known, so the referrals of very young children increased and the consequent wide age range at group sessions made activities and group discussions less effective.

Discussion with the young people and their families clearly indicated that the time had come to offer another level of service for the older age group. The interests and needs of adolescent and young adult carers required a different approach, with an emphasis on increasing life chances and resiliency.

What are the aims and objectives?

Aims:

- To support young carers during the illness and subsequent death of a family member.
- To reduce the extent of inappropriate caring roles.
- To alleviate the isolation of young carers.
- To enhance the life chances of young carers.
- To educate health, education and social care professionals about the specific, and often long-term, needs of young carers impacted by a terminal illness in the family.

Objectives:

- To provide emotional and practical support to young carers on an individual basis.
- To listen to young carers and encourage individual and group discussion on issues relevant to their lives and experiences.
- To involve multi-disciplinary team members, for example doctor, nurse, spiritual care worker in facilitating group work with young carers to enhance mutual understanding.
- To offer transport for those who could not otherwise access FRESH.
- To provide counselling and school liaison for all young carers as required.
- To demonstrate the importance of support for young carers in palliative care situations and to educate multi-disciplinary palliative care teams.

How is it funded?

FRESH is funded by Young Carers Grant Programme 2010, a programme managed by Carers Trust and funded by Comic Relief. The project is receiving £72,500 over three years, and any shortfall is made up from Hospice funds.

What has it achieved?

“I couldn’t talk about it before I went, but when I went to FRESH I felt I could because there had been others who had been through it.”

Young carer

“Our girls have found the group really helpful, especially to be able to talk with others.”

Bereaved parent

“It is such a relief to have somewhere to refer these kids.”

Community palliative care nurse

The FRESH group meetings provide a safe space for young carers to access multi-disciplinary support, a discussion group with their peers and a chance to enjoy recreational activities. These are well received by the young carers, their parents, professionals from education and youth services, and those who work in health and palliative care with the young carers' parents.

In particular, the peer support element of FRESH has resulted in marked improvements in young carers' confidence and overall wellbeing. With increased levels of confidence, young carers have been enabled to ask more questions of professionals involved in the parents' care, to feel more in control of their lives and be better advocates for themselves and their family members.

The active participation in FRESH by other staff at St Michael's and professionals from outside the hospice has been a tremendous advantage to both the young carers, the professionals who take part and the palliative care community. Medical and nursing staff have commented on the easier experience they have had during periods of patient admission with families who have already been involved in FRESH. As parents and children have already met with some of the professionals who will care for them during admission, communication has been easier and a trusting relationship has already been founded.

FRESH has raised awareness of young carers within the local community – with local social and education services, community and palliative care services and the wider NHS in Herefordshire. Most local professionals know of St Michael's Hospice and are increasingly more aware of its support for young carers. This is due in part to the young carers at FRESH; some were involved in the production of a short film promoting the family and group services on offer. This film was shown at the Hospice AGM and is used for training and information with Herefordshire health, education and social care providers. Other young people have given talks in schools and joined St Michael's Hospice schools education days as part of a panel speaking directly to teachers about the impact of terminal illness and death on family life.

There was a feature on FRESH and St Michael's Hospice in the teenage girls' magazine Shout in 2012. FRESH young carers participated in the Great British Menu does Comic Relief, and three young carers and a nurse were invited to the banquet held at the Royal Albert Hall to celebrate 25 years of Red Nose Day.

How have carers been involved in planning and delivering this work?

Young carers have been involved in all stages of planning activities and developing FRESH. They chose the name FRESH, standing for Friendship, Respect, Emotion, Support and Health, as these concepts covered the principal aspects of the support

service they wanted for themselves. There is a designated, purpose-built room for this older age range and young carers were involved in its design, furnishing and equipment.

How is the initiative run?

Most young carers supported by FRESH will have relatives under the care of St Michael's Hospice, but this is not a prerequisite. Referrals are welcomed from any source – health, education, youth and social services. It is hoped that in due course young people will self-refer. It can be very hard for any person – child or parent – to accept the need for hospice care as this entails recognition of a limited life prognosis and realisation of impending death. However, young carers are sometimes the first family members to use the services of St Michael's Hospice.

When young carers join FRESH, they are assessed using tools from the Manual for Measures of Caring Activities and Outcomes for Children and Young People¹. Ongoing assessment continues throughout their contact with the programme. It is common for young carers to be supported by FRESH for 18 months or so, and some have been attending since it started. Every young carer's situation is different; in addition to regular support for young carers who live locally, FRESH sees children who live elsewhere but make visits to see a relative under the care of St Michael's Hospice. Support for the young carers lasts throughout the time of palliative care diagnosis and then during the transition into bereavement. Memory Days and bereavement support will be offered to young carers and other surviving family members.

Various staff from the Hospice work directly on the FRESH project – a project lead (11 hours a week), a qualified palliative care social worker (20 hours a week), healthcare assistant (20 hours a month), staff nurse (15 hours a month). Other professionals, such as counsellors or complementary therapists, are brought in to provide a specific service as the opportunity arises. The team is overseen by a specialist palliative care social worker, project manager. In addition to the above, other hospice staff are brought in to support group sessions on a four month rota basis. This supports the aim of culture change within palliative care, helps to spread the word about FRESH and to further best practice in relation to young carers and their families.

At St Michael's Hospice a complementary therapist is generally available who can offer treatments and a listening ear to young carers feeling stressed or anxious. Such well-tuned care can make all the difference to a young person's experience and subsequent memories of this time of crisis, and to their ability to cope with both the short- and long-term impact of illness, death and bereavement.

Ongoing group and individual support is delivered at St Michael's Hospice, at a local youth centre, at the family home and on the phone. The frequency and type of support varies according to the young carer's circumstances and wishes. FRESH also acts as a link to bring isolated young people into mainstream community provision, supporting access to social services and welfare benefits, referring young carers to other groups, to dance or sporting activities, to youth centres, and encouraging attendance at college and evening classes.

1 Joseph S, Becker F, Becker S (2012), 'Manual for Measures of Caring Activities and Outcomes for Children and Young People'. Carers Trust.

When the staff from St Michael's Hospice are in contact with community palliative care nurses, social workers and other healthcare professionals, they stress the importance of always asking after clients' children and grandchildren as a way of establishing if there are young carers and how the family as a whole is coping.

Awareness of the service, as well as other support for younger children and their families, is promoted through a range of leaflets, radio adverts and a DVD which young carers helped with. A very active programme of FRESH staff visits to schools, colleges and general practices is underway and regular contacts with child and adolescent mental health services and youth offending teams are developing.

What methods have been particularly effective?

It has been easier to recruit young carers who have a family member who is already receiving care from St Michael's Hospice. Their relatives will already know and trust hospice staff and will have accepted their diagnosis. It is commonly very difficult for a person to accept that they are dying, even if that may be many months away. For a parent of dependant age children it can be exceptionally difficult, and may often be a factor in delaying referral to, or acceptance of, young carer support.

The peer support element whereby young carers can talk about the illness and impending death of a parent or grandparent, in a way they feel they could not with anyone else has been very rewarding. Some young people, for example, are troubled by thoughts that they wish their parent would die sooner so they didn't have to see them suffer and worry about them. It can be an enormous relief to recognise that others may sometimes feel this way also, and to learn that this can be a normal part of the grieving process.

Have there been any challenges along the way?

The most serious problem was the withdrawal of two planned partners within the first two months of setting up. One was an independent youth centre, and although FRESH does meet in their premises, the youth centre is no longer able to provide any direct youth service. The other was an independent healthcare service for young people – actual shared working has not happened although they do share information, make referrals and have regular meetings.

Promoting FRESH has been somewhat challenging. To quite a large extent St Michael's Hospice has relied on health and palliative care professionals recommending the service to families they meet. Moreover, since healthcare services focus heavily on the individual patient and their needs rather than the wellbeing of the wider family this means that doctors and nurses are not aware of young carer and whole family needs. Consequently, they are not familiar with the opportunities that exist to alleviate the social and emotional impact of illness and death on whole families.

Patient confidentiality can be a barrier if a person has not disclosed their health status to the young carers in the family. Hospice staff aim to gain the trust and understanding of all family members in order to support them as best they can.

What hints and tips might help me get started?

- It is important to create written service level agreements with partners before the project begins, to ensure commitment and an ongoing partnership.
- Consider the hours needed to resource the service. St Michael's Hospice has learned from experience that a project manager needs more than one hour a week.
- Make sure you have experienced professionals to work on the programme.
- Plan how you will promote your service. Plan recruitment policy and integration with mainstream provision.
- Educating other professionals about palliative care, young carers and bereavement should be an essential part of the programme.

Are there any useful documents or resources that could assist me?

Contact St Michael's Hospice for the video about its Family Services.

Ness, P (2012), 'A Monster Calls.' Walker Books. A young adult novel about the impact of a parent's terminal illness.

Where can I get further information?

St Michael's Hospice
Bartestree
Hereford HR1 4HA

www.st-michaels-hospice.org.uk

Sara Higginson
Specialist Social Worker and Project Manager
Email: shigginson@st-michaels-hospice.org.uk

Mary Taylor
Social Worker
Email: mtaylor@st-michaels-hospice.org.uk

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