

## **Introduction**

In 1992, Dr Ann Wallace, Consultant Paediatrician for the Chichester area, and Ward Sister Beth Connolly, asked families of sick children what their needs were when they left hospital and returned home. They found:

- a) Parents wanted to know more about their child's illness
- b) Parents wanted to be shown how to care for their child e.g. feeding through a nasal gastric tube
- c) Parents needed a nurse to care for their child, to give them time to care for other members of their family, or to give them a chance to have some time off for themselves
- d) Parents needed financial help - caring for a very sick child can put huge demands on resources, as invariably one parent will have to give up work

With no funds available to help these special families, in 1993 Co-Founders Kate Shaw, Diana Levantine and Frank Snell (who sadly died in April 2004), set up The Sussex Snowdrop Trust and its special Care at Home Team.

## **Fundraising**

Fundraising for the charity is incredibly important as approximately £300,000 is spent annually on direct family care, which includes paying the wages of Nursing Staff, Counsellors, and the Family Volunteer Coordinator as well as the urgent financial help that is given to parents.

## **Where does the money go?**

Snowdrop are delighted to announce that of all income received during the last financial year, 70% was spent on direct care for their children and their families. Approximately £350,000 is spent annually on direct family care, which includes paying the wages of our special Snowdrop Care at Home Team, as well as the urgent financial help that is given to parents. Here are some of the ways that money has been spent in the past:

Help with Petrol bills for parents travelling thousands of miles to take their child to and from hospital, visiting children, attending outpatient appointments and therapies.

Most trips to hospitals are made with the help of Snowdrop Family Volunteers who drive families in their own cars and the charity pays their expenses.

Pushchairs for sick children when it is impossible for the family to fund them.

Computers/laptops to help children who have missed days, weeks and sometimes years of schooling. To communicate with family/friends whilst in isolation wards and to be "a window to the world" whilst being housebound.

Washing machines/dryers for incontinent and very ill children.

A Fridge for a family to store special food, medicines etc.

Funeral costs. (All local funeral directors provide their service free for children under 16), but Snowdrop can pay for the extra's.

Helping with rent, electricity and other household bills which can soar when a child is ill.

## **Snowdrop Care at Home Team**

There are currently 92 Snowdrop children. Some spend time in hospital receiving treatment or undergoing an operation, but most are at home. The Snowdrop Care at Home Team helps families to cope with having a very sick child at home, surely the best place to be.

Headed by Dr Ann Wallace, Community Pediatric Consultant. The Team consists of :-

- a) Children's Community Nurses who administer treatment at home and school, give medical advice, teach parents to administer medicines and treatment, listen to problems and liaise with other Health Professionals.
- b) Nurse Support Workers who help with babysitting, take children to hospital appointments and support siblings.
- c) Counsellors who can meet families as soon as a child is diagnosed with a life threatening illness, to offer practical and emotional support if needed.
- d) A team of Volunteers provide transport for hospital appointments, babysitting, sibling support and, just as important, become a friend.
- e) A Family Volunteer Co-coordinator who meets and places suitable volunteers with families.