



Educational meetings

Most groups organise once a year or more often an informational meeting for parents. To help starting groups, we give you some tips and a list of topics that might be of interest. One of the doctors, nurses, psychologists, social workers, teachers or parents will certainly be willing to read a paper.

General

Place: Choose a central place, this can be the hospital but keep in mind that some people don't like to come (back) there. Sometimes a neutral place - conference centre - is a better choice.

Time: Choose a time when as many as possible parents can come, e.g. a day in the weekend. Reckon with distances and travel time, so don't start at 9 h in the morning and don't close at 9 h in the evening.

Other: Organise a program for the children and a babysitter for the young ones. That way parents don't have to bother about "who is taking care of my kids?"

Announcements: Announce the meeting in your newsletter, on posters on the ward and in the out-patient clinic, in local media and, if you have a membership list, send invitations to all group members. Inform the medical staff about the meeting a long time ahead so that they can tell the parents.

General medical topics:

cancer in children	home care
diagnostics	pain management
multidisciplinary treatment	long term effects
trials and protocols	long term follow-up
quality of care	new treatments: the future
bone marrow transplantation	

Disease related topics:

treatment of leukaemia, Hodgkin and non-Hodgkin lymphoma's, brain tumours, bone tumours, solid tumours, retinoblastoma, etc.
bone marrow transplantation in the treatment of ALL, neuroblastoma etc.

Psychosocial topics:

coping strategies	siblings
family dynamics	grieve and bereavement
the parent as part of the treatment team	long term psycho-social effects
school re-entry	rehabilitation
long term cognitive effects and remediation	

Other topics:

ethical issues	alternative treatments
nutrition	genetics