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

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

**Other topics:**
- ethical issues
- nutrition
- alternative treatments
- genetics