

Follow-up and aftercare from a patient's point of view

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1) Information

The society should know facts about childhood cancer:

- Cancer occurs also in children and adolescents.
- Cancer in children has a higher cure rate than cancer in adults; at the moment the survival rate is about 70 % (dependent on the type of the cancer).
- But: childhood cancer is still the second most frequent death cause for children living in Europe (after accidents).
- After successful treatment, most patients can live a normal life. However, some have to live with handicaps, that is physical and/ or psychological long term effects (less resilience, problems with concentration and attention, physical disabilities – e.g. amputation –, higher risk for a secondary cancer and/ or relapse etc.)

2) Awareness/ Behaviour

How former childhood cancer patients want to be seen and treated by friends, family, the public and also by doctors:

- „As normal as possible – as much consideration as necessary“ .
- We want to decide ourselves what we are (still) able to do and what we are (no longer) able to do, as well as what we want to do and what we don't want to do.
- We want to have the same chances, possibilities, and rights like others of the same age (not only job opportunities but also with respect to insurances).
- We expect to be honestly informed by our doctors in a way and language suitable for our age.

3) Follow-up and aftercare

Wishes/ Ideas for the medical and psychosocial follow-up and aftercare:

- We would like to have good medical care, even years after the illness.
- We want to know where to go with medical questions (to the paediatric oncology department, the oncology unit for adults, a general hospital, a general practitioner)
- We have special questions to our doctors (for example: what about fertility, or are there risks with a possible pregnancy, and what possible risks will our own children have?)
- We want to know, how long we should go to follow-ups.

3) Follow-up and aftercare

Wishes/ Ideas for the medical and psychosocial follow-up and aftercare:

- Some former cancer patients like to attend psychosocial meetings and like the exchange of experiences with other cancer patients, while others don't want to do this.
- We think that psychosocial programs are important for our development for the following reasons:
 - During the illness we often feel alone.
 - We can regain our self-confidence, can try out what we (still) are able to do and we can test our limits.
 - During the long time of the intensive treatment we are separated from our normal environment. In survivor groups we can learn a lot, we can meet many interesting people and can make new friends. It helps us to find our place in society.

Thank you for your attention!

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For more details, visit us on www.overcomingcancerwithresearch.eu