

Working with Children and Adolescents after Stem Cell Transplantation: An Outpatient Handbook

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Background

A large part of a child's care after Haematopoietic Stem Cell Transplantation (SCT) takes place in an outpatient setting.

Discharge from the SCT-unit is extremely exciting, however, the first time at home is often stressing and demanding for patients and families.

An outpatient-handbook was designed to provide patients and family members with comprehensive information on the life after discharge from hospital.



Aims

- To create a comprehensive information about SCT-aftercare
- To provide interactive education about health promotion, exercise, nutrition
- To prepare for and prevent side effects, complications and late effects that can occur after SCT
- To help children and adolescents to cope with illness, conditions and disabilities
- To support patients and families going through the hospital journey
- In an age-adjusted and entertaining way
- Useful, practical, easy to read



Methods

• Development:

A multidisciplinary team of nurses, doctors, psychologists, art-therapists, teachers, patients and parents was involved

• Design:

A main cartoon character („CELLY“) was designed by a professional illustrator to guide through the handbook. Pictures should provide entertainment



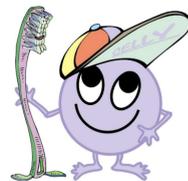
• Production:

Paper prints are done in the hospital according to the actual need. The handbook is created as a hardcover with a heat binding system, which provides a strong and permanent binding quality. For customization the book cover is printed with our own logo and cartoon.

Results

Age-adjusted versions:

Children: 4-11 years
Adolescents: 12-17 years
Adults and parents



Content:

Hospital administration
Medications
Haematological and immunological reconstitution
Acute and chronic GVHD
Organ toxicities
Infections: risks, prevention and treatment
Nutrition and dietetics
Revaccination
Rehabilitation
Reintegration in daily family and social life, school and job
Health dictionary
Interactive pages for questions and feedback

Conclusion

Handbook Benefits:

- + Reduced the need for numerous sheets
- + Comprehensive information
- + High acceptance by patients, parents and staff
- + Useful tool of communication, with possibility to encourage patients to ask specific questions
- + Excellent instrument for continuous feedback (of patients and parents to review handbook and discuss it with nurses and doctors)
- + Interactive pages may serve as an instrument of quality assurance



References

Kids first for health by Great Ormond Street Hospital
www.childrenfirst.nhs.uk

The Children's Oncology Group (COG) Family Handbook
www.curesearch.org/for_parents_and_families

