

STUFF - a creative approach to providing key information and guidance to newly diagnosed adolescent and young adult (AYA) cancer patients

Liz Sommer RN

Wellington Regional Hospital Blood and Cancer Centre, New Zealand
AYA Cancer Network Aotearoa, New Zealand

Background:

While a cancer diagnosis is challenging for anyone, the AYA patient population generally have little, if any previous experience with managing such a major life-changing event and as such may be more likely to experience confusion, anxiety, depression and loss of confidence than older patient cohorts. Their heightened developmental need for privacy and autonomy may also make them less likely to seek support and information or to express their worries to others.

Vision:

To create an age-appropriate interactive resource designed specifically for adolescents and young adults (AYAs) newly diagnosed with cancer. Part patient handbook, part journal **STUFF** is intended to provide inspiration, acknowledgement, reassurance and practical guidance and to act as something of a roadmap with which to traverse the messy, challenging terrain of cancer treatment as an adolescent or young adult.

Development:

Initial development began with conversations between long-time AYA patient Petra Kotrotsos, the AYA cancer Specialist Nurse at CCDHB and a highly talented volunteer, Ana Matsis whose experience in communication and publishing was invaluable.

Ten AYA patients, past and present were then invited to complete a short survey or to engage in a one-on-one interview to inform the content and format of the book. Five key content areas were identified and these became the “chapters” of **STUFF**. Direct quotes from these interviews appear throughout the booklet to highlight the concerns commonly experienced by AYAs and to provide inspiration and reassurance.

The title “**STUFF**” (I need to know) - Ngā mea me mohio au - was chosen to reflect the messy mix of issues facing this special patient group and to veer away from more medically focused resources. Special thanks to AYA Lani Hirini for her Te Reo Maori translations of the chapter headings.



Content & Production:

- The five topic areas chosen were –
1. The Heart, Head and Social **STUFF**/Te ngakau, te hinengaro, me nga mea pāpori – feeling scared, sad, out of control and all those other big emotions; stuff that seems weird; impact on future plans, education, relationships, sexuality and more
 2. **STUFF** that might help/Ngā mea hei awhina pea – ideas for maximising support and self-care
 3. Treatment **STUFF**/ Ngā mea maimoatanga – what to expect, explanation of medical terms, tests, scans, treatment modalities, blood results
 4. Useful **STUFF**/Ngā mea whaipanga – contact details for hospital departments, recommended websites and useful support organisations
 5. Personal **STUFF**/Ngā mea matawhaiaro – blank space allocated for patients’ personal reflections (writing, drawing, scribbling etc) and suggestions for creative self-expression

A focus group of AYAs generously gave their feedback on an initial draft to fine-tune both content and design. They offered a clear message about style, emphasising that it needed to be friendly and relaxed rather than clinical or “preachy”. A repeated reminder was that everyone’s experience of cancer is unique and that while your own feelings and perceptions may be different to other AYAs they are equally valid and worthy of acknowledgement.

Outcome and Future Possibilities:

STUFF has been well-received by AYAs and would naturally lend itself to being produced in a digital format in the future. It is currently being edited for use at Canterbury DHB and may also prove useful for those working with adolescents and young adults diagnosed with other significant or chronic health issues.

Acknowledgements:

The fully fledged version of **STUFF** was produced with a raft of generous contributions from the funders (Wellington Hospital Foundation), designers (Moxie), printers and paper merchants but most importantly of course the young AYA cancer patients and survivors who gave their time, energy and wisdom to help make the journal the best it could possibly be.

