

## Joint Interactive Symposium SIOP-NG/EONS

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### Teenagers with cancer: what do we know about their cancer trajectory

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The incidence of cancer in adolescents is higher than in children and is increasing more quickly in the older than in the younger age group. Furthermore, the degree of improvement in survival rates is less in adolescents than in children. In part this difference reflects the distribution of cancers in the adolescent age group, which is transitional between those in children and adults; malignant lymphomas, germ cell tumours and brain neoplasms predominating. The common cancers of pre-school age children are mostly absent in adolescents and carcinomas, especially of the thyroid, begin to assume more importance. Compounding the difficulty improving the survival rates for adolescents with cancer is the low accrual of patients in this age group to clinical trials. But survival is not enough. Adolescents afflicted by malignant disease have particular needs in the areas of psychosocial and supportive care as they face the challenges of moving from childhood to adult life. There are particular needs in the areas of peer relationships (including issues of body image and sexuality), family dynamics, (including effects on parents and sibling) and social integration (including education and employment). And the challenges continue beyond the completion of therapy as these young cancer survivors deal with transitions in care, health risk behaviours and the late effects of treatment, among other obstacles to normalization of their lives.

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### What is different about caring for teenagers with cancer?

S.J. Morgan, *St James's University Hospital, Teenage Cancer Trust Unit, Ward 10, Leeds, United Kingdom*

Historically teenagers and young adults with cancer have been cared for either on Paediatric or Adult Oncology Units. Neither of these are appropriate, and many young people and professionals, felt that these young people were 'misplaced'. Recently in the UK there has been a major drive to ensure that the needs of these young people are beginning to be acknowledged and addressed. This follows the 'Calman - Hine Report' (1995) which stated that purchasers should look for opportunities to develop cancer services to this age group. Many professionals ask why young people need to be treated differently, and you only have to talk to them to find out. When asked, they express the need for control in their care and the wish to be fully informed about all aspects of their disease. They would like to be in an environment which is neither child or adult orientated, but designed to meet their, usually very specific, requirements! They have educational and employment needs, issues of sex and sexuality, relationships, fertility, loss of future, dependence/independence and, importantly, they wish to have a 'voice' in their care. In order to achieve the ideal model for caring for these young people a highly motivated team is needed who will provide the expertise required to address these issues. It is desirable to have 'Teenage and Young Adult Units', but these are expensive, and it is possible to develop a 'virtual' unit, where the expertise is delivered to the patient wherever they may be cared for. This model is being developed in Leeds, UK and runs alongside a 6-bedded Teenage Cancer Trust Unit. Much work has been initiated between the professionals, patients and their families who are working together to answer the question, 'What is different about caring for teenagers with cancer?' and putting it into practice. The findings of this will be shared at this Symposium.

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### The teenager perspective: what is the reality

S. Thykaer, *N. Hove. Aarhus Kommunehospital, D1, Aarhus, Denmark*

Susanne Thykaer, a oncological nurse, is interviewing a former patient, Susanne Vestergaard, who will be telling her story about 1 1/2 years of teenage life, with disease, treatment and rehabilitation.

Susanne Vestergaard was, when she was 17, diagnosed with bone cancer, in one of her knees. She was treated at the University Hospital in Aarhus. The treatment was chemotherapy, operation (kept the knee) and finally more chemotherapy. During the period, Susanne Vestergaard, was living in Vejle, approximately 70 km from Aarhus. She was living with her family, parents, brother and sister. Today she is living in Aarhus as a medical student.

Susanne Thykaer is working as a trained nurse at the University Hospital in Aarhus, Aarhus Kommunehospital. Susanne Thykaer graduated as a nurse in 1983. Has been working as an oncological nurse 1994. She has participated in the development of a teenagers unit (age 15-21). It is the first "Youth" unit in Denmark. From 2000-2002 it was a pilotproject and now it is established as part of the Oncological department in Aarhus.

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### Teenagers' participation in research - how to recruit and maintain interest

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With the current move towards consumer involvement and patient/public participation in the evaluation and planning of care (Department of Health 2000) it is becoming increasingly necessary to ascertain the views of young people about their care and perceptions of the services provided. However, there is little written about working with this age group. Ways of addressing approaches to engaging teenagers in the research process remain an exciting challenge.

The challenges faced are associated with adolescent developmental capacities, developmental change and stability, gender and ethnicity (Dashiff 2001). The application of theoretical and empirical knowledge about adolescent development can strengthen data collection instruments and procedures. Innovation and creativity within a participant-focussed philosophy must also be adopted if researchers are to motivate teenagers to want to participate in research.

This presentation aims to draw on the experiences of a programme of research in order to provide practical examples of working with teenagers on research projects. A number of research techniques have been found to be more effective with young people such as focus groups, graffiti wall, diaries and information technology (Dashiff 2001). The aim with all methods is to work flexibly offering a range of activities and resources, which draw on play and participation based approaches (O'Kane 2000). The biggest challenge for researchers working with teenagers, are the disparities in power and status between teenagers and adults (Morrow and Richards 1996). The aim is to find ways to break down this imbalance by creating space, which will enable teenagers to speak up and be heard.

### References

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