

# Paediatric Cancer in Malta

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**The illness we call cancer has extraordinarily diverse features including its causation, underlying pathology, clinical symptoms, therapeutic response, and outcome or chance of cure. It is a collection of many disorders of cell and tissue function that have one special biological property in common - the territorial expansion of a mutant clone. Cancer develops as a chromosomal gene disorder in single cells. That cell or those cells with the right mutation or combination of mutations will form the winning clone that will acquire the ability to proliferate uncontrollably and spread locally and distantly in spite of the body's natural defence mechanisms against such rogue cells.**

## An overview

Around one in three of us will at some time have an unwelcomed diagnosis of cancer. In the developed world with the eradication of infection and malnutrition as major causes of mortality, cancer has largely by default, become more prominent as a life-threatening illness in children, although its frequency in the young remains very low. About 1% of all cancers diagnosed up to the age of 75 years occur in children and the incidence of the disease worldwide is 110 - 130 per million children per year. The relative risk for a child to get cancer up to

the age of 15 years is 1 in 600. Compare this to the risk of 1 in 3 for an adult up to the age of 75.

The spectrum of the disease is different in children when compared to that in adults. Epithelial cancers or carcinomas like those found in the breast, lung, colon, prostate, cervix, uterus and skin are extremely rare in the paediatric age group. The most common cancers in children are the acute leukaemias and lymphomas, brain tumours, the various sarcomas and the embryonal tumours particular to children. These cancers are as a group more

responsive to chemotherapy and radiotherapy than the epithelial cancers found in adults with the corresponding better survival and cures in the paediatric age group.

Nowadays with modern combination chemotherapy combined with modern surgical techniques and radiotherapy more than two thirds of children with cancer can be cured. In fact in the western world about 1 in every 1000 adults is a survivor of childhood cancer. This improvement in survival is also due to better supportive care, the treatment of children with cancer in specialised units and the ongoing national and international trials that try to answer questions about the disease and its treatment and which have inevitably resulted in better cure rates with the least harm.

## The local scene

Cancer in Malta affects around ten children under the age of fourteen years every year. A third of these will have leukaemia and another third will have a brain tumour, the rest will have one of the sarcomas or embryonal tumours particular to the paediatric age group. The treatment of children with cancer in Malta has over the last ten years undergone some fundamental changes that have made our cure rates comparable to those of the rest of Europe and the treatment itself less hard for the family and child.

More than ten years ago the treatment of children with cancer used to be

### The twelve major diagnostic groups of cancer in children are:

Leukaemia	39.8%
Lymphoma	11.3%
Brain and spinal	27.0%
Sympathetic	8.8%
Retinoblastoma	3.7%
Kidney	7.6%
Liver	1.2%
Bone	5.1%
Soft tissue sarcoma	7.7%
Gonadal and germ cell	3.7%
Epithelial	3.3%
Other	0.4%

undertaken, as used to happen in other more developed countries, by adult oncologists in conjunction with paediatricians. The treatment, although based on the best protocols available at the time, was usually carried out on a general paediatric ward by persons with little training and experience in the care and management of children with cancer. In many of the cases the patient had to be sent abroad for treatment in centres that specialised in the treatment of paediatric cancer. This, together with the diagnosis of cancer and the uncertainties of the child's future, brought a lot of hardship and anguish to the families concerned. The success of treatment does not depend only on the protocols and chemotherapy used but to a large extent on a multidisciplinary team that is specialised in the treatment of paediatric cancer working in a centre that has a modern diagnostic and therapeutic infrastructure.

Although we cannot be expected to provide all the care locally, especially the more specialised cancer treatment, because of the small number of cases involved, in most instances the treatment is carried out by local paediatricians and nurses trained in the care of children with cancer in a dedicated area away from the busy general paediatric wards. The advent of paediatric surgery, neurosurgery and modern radiotherapy techniques on the island together with modern laboratory and radiological diagnostic methods combined with efficient and state of the art blood transfusion and pharmacy departments has meant that most of the children with cancer can now receive all of their treatment on Wonderland Ward at St Luke's Hospital.

As already mentioned not all the children can have their entire treatment locally mainly because the speciality does not exist or the necessary supportive care is not available. One case in point is bone marrow transplantation or very high dose chemotherapy treatment requiring Peripheral Blood Progenitor Cell rescue. Others include specialised cancer surgery, especially in certain areas of the brain and abdomen, and certain specialised radiotherapy techniques.

However in most cases the diagnostic workup and the conventional treatment essential and prior to such aggressive and specialised treatment is carried out locally, therefore minimising the hardships for the patient and his or her family.

One must also mention the valuable foreign contacts that have catalysed and made possible the present state of affairs. Our long and precious friendship with specialists from paediatric oncology centres in the Royal Marsden Hospital and Great Ormond Street Hospital have resulted in the various local specialists who are now working as a team in the field of paediatric oncology. The modern advances in information technology have made it possible to discuss difficult cases with foreign specialists in a short period of time to the benefit of our young patients.

### What else?

Cancer does not occur in a vacuum but usually affects a child who up to a few months or weeks before was a healthy member of one of the various family units that nowadays are the norm in our society. The parent or parents will be working hard to raise and support the family and to give the best education and upbringing to the affected child and his or her siblings. The grandparents look at their children and their families with satisfaction and joy. All this collapses when cancer is diagnosed. The child is admitted to hospital for tests and treatment for periods ranging from a few days to weeks and sometimes months. One of the parents will have to take time off from work or resign from his or her job completely. The other siblings are quite frequently neglected because most of the attention is now focused on the affected child. There is a lot of anxiety and fear that shakes the whole family unit and permeates through the rest of the extended family. Feelings of guilt increase the tension within the family and past problems between family members resurface and threaten to break up the family. It is especially hard for single parent families and for low-income families. Life will never be the same for the parents and the rest of the family of the

affected child. Sometimes treatment has to be given in a specialised centre abroad and, although the government pays for all the medical treatment, the financial burden on the family will still be substantial. When this is combined with the lack of close family ties in foreign countries the strain on these families will be tremendous. The child may miss out on school at a critical stage of his formative years.

It is for these reasons that the Puttina Cares Children's Cancer Support Group was formed. It is composed of professionals working in the field of paediatric cancer, parents of children that have received treatment for the disease and persons who voluntarily lend their support and time to improve the plight of children with cancer. The aims of the support group are:

1. To advocate on behalf of affected children and families by representing their needs.
2. To campaign for the provision of a coordinated network of care and support.
3. To promote models of good care and practice.
4. To support families with a national information service.
5. To enhance the knowledge and skills of professional carers by providing specialist literature and education opportunities.

Since its setting up, towards the end of 2001, the support group has actively participated in the following projects:

1. The renovation of Wonderland Ward. This included the redecoration of the single rooms, new furniture, television and Playstation equipment, extra wall mounted beds for the parents and air-conditioning equipment.
2. A modern pantry where the parents can do most of their cooking if they wish too.
3. A new automatic washing machine and dryer.
4. A new playroom.
5. The support group is at present in the process of completing a classroom in

Wonderland Ward equipped with computers for the use of the children on the ward.

6. The group has also advocated for the children and their families who come from Gozo or need to go abroad for treatment so that the cost of travelling would be given at a special reduced price.
7. The group has also organised several recreational activities for the children and their families. These included Christmas and other parties, BBQs and boat trips.
8. Some of the children and their families have also benefited from leisure trips abroad free of charge or at special reduced prices.
9. The group has also obtained the services of social workers, psychologists and a spiritual counsellor to tackle some of the difficult social and emotional problems that the families present with.

The support group meets regularly, at least once a month, to plan new projects and assess the ongoing ones. Obviously none of this is possible without the generous help of sponsors like the HSBC, through its Help the Children Fund, and others that are too numerous to mention individually. In fact one of the group's main functions is to obtain funds and other resources from the various sponsors and most members of the group have at one point or another taken part in fund raising activities. The group also aims to create more awareness about cancer in children, not just the ugly side of the disease but also the fact that in most cases it is a curable illness. The support group also aims to remove the stigma of doom and death attached to the word cancer. It is true that cancer is a ruthless disease that is in most cases difficult to cure and may affect people in their most productive or formative years. However for the past twenty years or so, a

lot of advances have been made in its treatment especially in the field of paediatric cancer. Consequently a number of members from the support group have appeared on the media to promote its activities, create more awareness about the disease and its treatment and most important of all to advocate for the patients and their families.

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