Personally Speaking

By Mr Rajakanth

Take charge of your life! Image: state stat

This is the third in a series of articles on Club Rainbow – the adopted charity of the Singapore Medical Association. In this issue, we examine how volunteer doctors can play a lead role in helping families make the lifestyle adjustments necessary in living with chronic illnesses.

"I feel I do not have control of my life anymore. Someone is always telling me what I cannot do!" This is a sentiment we often hear from parents whose lives have been changed forever because of their children's chronic illnesses.

For the children too, trying to cope with their affliction means following an endless string of precautions and when in doubt, the mantra which has been drummed into their heads is always to err on the side of caution.

The end result is often frustration, anger and resentment – hardly the right emotional mindset they would need to cope with the inevitable sacrifices that have to be made along the road ahead.

While counselling provided by Club Rainbow can and does help families to accept what they cannot change, empowering parents and children to take charge of their lives will give them a much needed confidence boost and hope for the future.

This is where doctors can play a key role in organising talks to give parents a more rounded understanding of their child's illness and the options before them. For the older children, they too need to learn the ropes in taking responsibility for their continued medical treatment.

Living in the Internet age means having access to a tremendous amount of information about illnesses, new discoveries and treatment regimes. There is no doubt that much of it may be useful, but not everything on the Net is accurate or relevant to the particular needs of an individual.

While the child's physician must remain the primary source of information for parents, these talks will give our Rainbow families an opportunity to hear directly from the experts in various fields. It also provides a platform for discussion and the sharing of ideas.

The majority of children at Club Rainbow are divided into one of five major illness groups. They are:

- Thalassaemia Major;
- Biliary Artesia;
- Congenial Heart Diseases;
- Spina Bifida and
- Premature babies with very low birth weight and chronic complications.

Each year we try to organise at least three illness-specific talks for each group. In addition, we also hope to organise talks on more general topics such as nutrition, coping tips, sports and physiotherapy, and hygiene.

Doctors, if you would like to help us by sharing your expertise with our families, please contact us. We welcome your suggestions on the topics and issues to be discussed. You can reach us at 6377 1789 or email **contact@clubrainbow.org**

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