

## "Those around me are well supported"

This is one of Macmillan's 'Nine Outcomes' - statements that all cancer patients should feel they can make about their care. Yet there is good evidence that the needs of many of those supporting cancer patients are still not adequately addressed.

I was diagnosed early	I understand, so I make good decisions	I get the treatment and care which are best for my cancer, and my life
Those around me are well supported	I am treated with dignity and respect	I know what I can do to help myself and who else can help me
I can enjoy life	I feel part of a community and I'm inspired to give something back	I want to die well

**Young people with cancer say that they want those around them to be given information and support.**

They recognise that, by getting this, their family, partners and friends will not only get help to deal with the impact of the cancer diagnosis itself, but are likely to be better equipped to give support and help to the young person him/herself.

**All staff working with young people should ensure those supporting their patients get good quality information**

## RESOURCES

### Macmillan Cancer Support

The Macmillan website has a special section for TYA patients. This includes a useful booklet - *I'm still me* - which offers insights into how it is to be a young person with cancer.

<http://www.macmillan.org.uk/Cancerinformation/teensandyoungadultsInfoforteensandyoungadults.aspx>

Macmillan also have Benefits Advisers who can help with information about finances and benefits



### Teenage Cancer Trust

The Teenage Cancer Trust website is a good source of information directed towards young people themselves. This can also be a helpful resource for friends and family.

<https://www.teenagecancertrust.org>



### CLIC Sargent

The CLIC Sargent website has a useful section starting with some information for young people about how cancer might affect them, and includes short sections on their relationships with others.

<http://www.clicsargent.org.uk/content/how-cancer-affects-you>

### The South West TYA team

The Principal Treatment Centre for TYA with cancer is in Bristol, at University Hospitals Bristol NHS Foundation Trust, but partner teams deliver care across the region in Truro, Plymouth, Exeter, Taunton, Bath, Cheltenham & Gloucester. TYA Specialist Nurses and CLIC Sargent Social Workers cover all these sites.

## SUPPORTING THOSE CLOSE TO A YOUNG PERSON WITH CANCER

**Information for professionals caring for a Teenager or Young Adult (TYA) with cancer**

*"It felt distressing and overwhelming to see my daughter so ill"*

*"I felt that if I asked for help I had failed"*

*Sometimes I felt too exhausted to be of any help"*

*"I was getting a lot of messages saying that 'you must be strong for him' ..."*

*"Support for those around me is the most important thing for me"*

**TYA PATIENT**

## WHAT WE KNOW ABOUT...

### Those around the patient

Some of those most significant in the life of a TYA patient may be individuals who extend beyond the immediate family and who can only be defined by patients themselves. As a result, although parents and other close family members remain very important in supporting young people with cancer, the terms 'family' and 'carer' may not always be appropriate for this network of supporters. The term "Patient's Network" has been coined to describe this wider pool of contacts, individually sometimes referred to as 'networkers'.

***"I don't think he told me everything.....so I worried!"***  
*(parent)*

### What TYA patients think

Young people want those around them to have information and support.

They worry about the burden of their illness on those closest to them but may not always be able to talk to them about what they are going through.

They are not always able to move on at the end of treatment even if their family and friends think it's now all over.

### What Networkers experience

Networkers offer support to patients in many different ways. Almost all feel that they offer emotional and practical support of different kinds and that they maintain this throughout the period of treatment, and afterwards.

Parents and partners, in particular, offer a great deal of physical caring and many also provide financial support.

***"I didn't have any energy left for leisure activities"***  
*(girlfriend)*

Almost all those close to the patient report a moderate or high impact on their personal well-being; social life; spare time & leisure activities; and on their financial situation - particularly during the patient's treatment.

The majority also report that they experience significant difficulties in relation to their responsibilities for, and relationships with, other family members. For some, there can also be an important impact on relationships with work colleagues and on wider friendships.

**These findings underline the high personal cost paid by the family, partners and close friends of TYA with cancer, and the significant impact on their wider family and social / work relationships.**

Many do not feel they are able to access useful information from any source.

### What Networkers want & need

They find it difficult to rely on the patient for information and often worry about how accurate and relevant information is that they seek for themselves. Some, but not all, would find it helpful to have an introduction to others who have been through a similar experience. They most value getting information from those directly involved in the patient's care.

Areas in which advice and information are most needed include: where to find / how to get emotional support; practical and financial guidance; specific information about the illness and its treatment; how to manage their relationship with the patient; and advice about their own physical wellbeing.

### TAKING ACTION

- **Make sure that young people know where their 'networkers' can go for help.**
- **Remember that helping those closest to the patient supports the patient too.**
- **Give the patient resources to pass on to their family & friends — it will save them from having to keep retelling their story**