



## SUPPORTING ADOLESCENT AND YOUNG ADULT SIBLINGS OF CANCER PATIENTS: THE FAMILY CONTEXT

All family members are affected when a child is diagnosed with cancer. Adolescent and young adults (AYAs) who have a brother or sister with cancer may experience a range of different feelings, such as anger, guilt, resentment, isolation, fear, worry, sadness, distress and anxiety. Siblings are therefore at increased risk of social, emotional and behavioural problems.

The way the family functions and copes with the situation will also influence its impact on siblings. Therefore, it is important to understand and address the needs of siblings in the context of the family. Providing siblings and families with appropriate support and services to help them through their cancer experience is essential.

This Paper reviews the current research on this topic and highlights important considerations for supporting siblings.

**This Research to Practice Paper has been prepared by CanTeen Australia in collaboration with the Research to Practice Advisory Group. A full list of the Advisory Group can be found on the CanTeen website.**

CanTeen Australia is the National Support Organisation for Young People Living with Cancer. It provides an Australia-wide peer support network for 12-24 year-olds: namely, patients - young people who have been diagnosed with cancer; siblings and offspring - young people who have an immediate family member (brother, sister, parent or primary carer) who has been diagnosed with cancer; and, bereaved siblings and offspring - young people who have had an immediate family member die from cancer. Driven by its mission to support, develop and empower young people living with cancer, CanTeen has a clear focus on meeting the needs of these young people through its programs, services, resources, research and advocacy work.

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AYAs refers to adolescents and young adults aged 12-24 years

Sibling/s refers to AYAs who have a brother or sister with cancer

Child refers to the individual with cancer aged 0 – 24 years

Family refers to all families including two parent, single parent and blended families

Parent/s refers to the primary caregiver/s of the child with cancer and sibling/s

# THE SIBLING EXPERIENCE

Every year approximately 1000 AYAs are diagnosed with cancer [1]. Each patient (on average) will have one sibling. Therefore, each year approximately 1000 young people face the challenge of having a brother or sister diagnosed with cancer.

AYAs are in a rapid period of physical, emotional and social change. For AYAs who have a brother or sister with cancer, this time of significant change and development is coupled with this additional stressor. The increase in stress can inhibit siblings moving successfully through developmental stages [2].

There is a growing body of literature relating to the siblings' cancer experience. The effects of having a brother or sister diagnosed with cancer are complex and some siblings may not have the cognitive skills and emotional maturity to understand and cope with their conflicting thoughts and feelings [2-4]. Although many of the effects on siblings are negative (see Box 1), positive effects have also been reported (see Box 2).

Adolescent siblings have demonstrated poor levels of adjustment to a childhood cancer diagnosis in their family when compared to adults and younger children [2]. A recent study found that 57% of siblings aged 12-24 years had high to very high levels of psychological distress [5] compared with 9% of young people in the general population [1]. Other studies have found that the percentage of siblings of cancer patients experiencing clinical levels of depression and anxiety are higher than the general population [2].

Some pre-existing individual factors [6] might increase siblings' psychosocial risk, including:

- **stress in other areas** e.g. school or work;
- **difficult relationships with parents or the ill child;**
- **ineffective coping skills** e.g. aggression or rebelliousness;
- **involvement in risky behaviours** e.g. alcohol use, drug use or self-harm;
- **existing mental health issues;** or
- **existing care duties for other family members.**

The following factors should also be considered when determining the impact on siblings [7]:

- **age** e.g. sibling needs will vary depending on their developmental age; and
- **gender or birth order** e.g. increases in responsibilities may be greater for females or for older siblings.

## Box 1: Negative effects reported by siblings

The majority of studies report the negative effects for siblings [2, 7, 8], including:

- feeling **anxious** about what will happen to the ill child and **fearful** that they might die;
- excessive **worrying** about their own health and that they too may get sick;
- feeling **guilty** that they are not the ill child, that they did something to cause the cancer or for wanting attention from parents while their brother or sister is ill;
- feeling **less valued** than the ill child;
- feeling **isolated, ignored, invisible** or '**second best**' due to a lack of attention and acknowledgement from parents, significant others and healthcare professionals;
- feelings of **anger, resentment, and jealousy** as the family's time and resources shifts to the ill child;
- feelings of **helplessness** as they are unable to make the ill child better;
- feelings of **sadness, grief or loss**, e.g. for the way life was before or for what the ill child is going through, long-term loss of childhood, or grief if their brother or sister dies;
- feeling that **friends don't understand, disconnection** and **social isolation** that may lead to difficulties with peer relationships at a time when these are important to adolescent development; or
- loss of **sense of self.**

Siblings may experience psychological distress at various points on the cancer journey, e.g. at the diagnosis of the ill child, after the ill child has finished treatment, or late onset distress as the sibling moves through developmental stages and gains a greater awareness of the meaning of cancer [2, 3]. A number of factors relating to the cancer journey may put siblings at greater risk, including [7-9]:

- an **unfavourable prognosis** for the ill child;
- **intensive treatment** and **lengthy hospitalisation** of the ill child e.g. this may increase the time that the sibling spends away from the ill child and parent/s;
- **visible side effects for the ill child**, e.g. this may increase the sibling's levels of distress, anxiety and worry;
- **long-standing physical and psychological health problems for the ill child** e.g. cognitive impairment may cause distress for siblings or lead to them experiencing grief and loss for the long-term effects on the ill child; or
- **siblings who become patients themselves** e.g. siblings who are stem cell or bone marrow donors may experience feelings of failure or guilt if the ill child does not get better.

Not all siblings will experience adjustment difficulties and positive changes can occur as a result of a struggle with a highly challenging life circumstance, such as a cancer experience [9].

### Box 2: Positive effects reported by siblings

Positive effects reported by siblings include [2-4];

- increased **sensitivity, compassion** and **empathy** towards the ill child and other individuals;
- increased **pride** and **respect** for the ill child and their accomplishments;
- **pride** in their own achievements during a time of stress;
- increased **family closeness** and **cohesion**;
- increased sense of **independence** from the roles undertaken during the cancer experience, and the support and care they may have provided to other family members during a time of stress;
- **maturity** and **resilience** from successfully coping with the experience of having a brother or sister with cancer;
- increased **appreciation of life** and their own good health; or
- increased **altruism, hope** and **self concept**.

## The needs of siblings

Research undertaken by CanTeen in conjunction with the University of Sydney [7, 10] revealed that siblings have needs in a number of domains including:

- information about the ill child's cancer;
- 'time out' and recreation;
- support from their friends and other young people;
- help dealing with their feelings;
- understanding from their family;
- help with their relationship with the ill child; and
- practical assistance.

Addressing the needs of siblings is important as poorer psychological functioning has been found to be associated with higher levels of unmet need [5, 10].

The following needs were the top ten needs identified by siblings of cancer patients as **not** being met [5]:

1. information about the side-effects of the ill child's treatment
2. information about the impact that the cancer and treatment may have on the ill child's life in the future
3. to be informed about the ill child's condition - good or bad

4. support from their friends
5. to know ways of giving emotional support to the ill child
6. to have 'time-out' with the ill child away from 'the cancer'
7. to be able to have fun
8. help with feelings about the possibility that the ill child with cancer might die
9. somewhere to go when it gets too hard to deal with the ill child's cancer
10. help dealing with sadness related to the ill child's cancer

## THE EFFECTS ON SIBLINGS IN THE FAMILY CONTEXT

A child's cancer diagnosis can put the family under great stress. Understandably, the focus of the family often shifts to the needs of the ill child. Consequently, siblings may be given more family responsibilities and be expected to become more self-sufficient. In some instances siblings become over-involved in the needs of the ill child, which can cause restrictions in their daily lives and overall development [11, 12]. Siblings have reported the following changes relating to the family context:

- **limited time** and **attention** from parents;
- **changed roles and responsibilities** e.g. some siblings may take on more household chores and care-giving responsibilities;
- **decreased sense of security** which the family typically provides;
- **restricted communication** with their parent/s and/or the ill child;
- **internalisation of feelings** e.g. siblings may hide their feelings as they do not want to add to the already high levels of stress for their parent/s;
- **loss of normalcy and predictability** e.g. the family may relocate or experience long periods of separation, routines may change, activities such as sport and time with peers may be restricted, and greater independence with schoolwork may be required;
- **diminished sense of self** and **importance** within the family [13];
- **sense of loss for family life as they knew it** and **coping with a new 'normal'** e.g. things may never go back to how they were before the family's experience with cancer.

Siblings may also experience positive effects relating to the change in the family context as outlined in Box 2.

# FAMILY RELATIONSHIPS

The unpredictable and uncontrollable nature of cancer can challenge and disrupt the family as a whole and it is likely that individual relationships will undergo change. It is important for health professionals to establish who the family members are and to understand the inter-relationships and inter-dependencies operating within the family.

## The parent-child relationship

Parent-child relationships influence a child's development, adjustment and wellbeing [14]. Following a child's cancer diagnosis parents often need to balance the needs of siblings with the needs of the ill child. This can lead to changes in parental monitoring, involvement and availability, and discipline practices of the siblings and ill child [14]. Levels of closeness and communication within the family may also change [14, 15]. Parents may become overprotective or indulge the ill child, develop closer bonds with the ill child, and place greater expectations on siblings [14]. Parents may try to protect siblings, and may not know how or what information to share with them [16].

The needs of siblings may be overlooked by parents who may not notice internalising behaviours (e.g. anxiety, depression) or may dismiss externalising behaviours (e.g. acting out, poor school performance, withdrawal) as 'normal' adolescent behaviour or 'attention seeking'.

"The relationship I had with my parents was minimal because my parents were dealing with their own stuff and at the hospital all the time, so we didn't talk."

Emilee -16 years  
CanTeen Bereaved Sibling Member

## Facilitating positive parent-child relationships

**Encourage open communication between parents and siblings** – parents need to be encouraged to check in with siblings, ask them how they are going and provide opportunities for them to openly share their feelings. Open communication can increase siblings' understanding and awareness of the situation, and decrease feelings of isolation, loneliness and anxiety [14, 17].

**Encourage parents to spend individual quality time with each of their children** – although it can be challenging for parents to find time it can help siblings feel valued and meet their needs for attention and acknowledgement [16].

**Encourage parents to adjust any differential parenting or favouritism as quickly as possible once the ill child is well** – this will help restore positive parent-child relationships.

**Encourage parents to consider whether the extra responsibilities being undertaken by siblings are age appropriate.** Extra responsibilities can make some siblings feel independent, helpful and capable. However, others may feel pressured and resentful towards their parents and the ill child.

**Encourage parents to keep siblings informed in an age appropriate manner** - siblings desire and need accurate information, particularly from their parents [18]. Open and honest information helps to clarify any misunderstandings that the siblings may have regarding the ill child's cancer and helps them understand the changes occurring within the family [18, 19]. Keeping siblings informed can also decrease their levels of anxiety and worry.

## Cultural consideration

*Stigmatisation of illness and other cultural or religious beliefs may influence a family's response to the cancer diagnosis [20]. Language barriers and lower health literacy may lead to higher levels of distress for parents who have difficulty understanding and using health information and engaging with support services.*

*Siblings in families with language barriers may be particularly vulnerable, as a lack of parental understanding and knowledge of the situation may inhibit communication with the sibling regarding the situation. When working with families from diverse backgrounds, it is important to consider cultural values and norms to help understand family communication [20].*

## Sibling relationships

There are clear associations between the quality of sibling relationships and sibling adjustment and development. The sibling relationship is considered the most enduring relationship and affects individual development throughout life [13].

A child's cancer diagnosis may see siblings form closer bonds, whilst on the other hand it may cause upheaval to their relationship [21]. There may be less opportunity for companionship between the ill child and sibling, and siblings may feel a sense of loss as the relationship changes. This can intensify pre-existing sibling rivalries or conflicts.

### Facilitating positive sibling relationships

**Explore the pre-existing sibling relationship** in order to fully understand the levels of conflict/competition (e.g. sibling rivalry) and companionship (e.g. sibling alliances) in the relationship [22].

**Gain an understanding of the individual expectations** of the sibling relationship and ensure that the wishes of each child are respected.

**Offer siblings the option of being actively involved** as this can help to maintain close sibling bonds and a sense of family. It may help foster a sense of connectedness and minimise feelings of loneliness and abandonment [18]. It can also help siblings to see the physical changes of the ill child gradually and allows siblings the opportunity to become more familiar with what the ill child is experiencing [18].

**Provide opportunities/programs for siblings to interact with their brother or sister** and encourage them to share their feelings in a safe environment.

### Cultural consideration

*In some non-Western cultures siblings' daily lives are highly intertwined, and sibling caretaking and companionship are routine [23]. This may result in siblings undertaking greater levels of responsibility than would be expected in traditional Western culture.*

## FAMILY FUNCTIONING

A cancer diagnosis can disrupt a family's usual routines, roles and patterns. Stable and structured family relations, good intra-familial communication, and supportive relationships can help families adjust to the changes required at this time [11, 24].

A number of different models have been used to assess the impact of illness on the family and its members. For example, the Calgary Family Assessment Model [25], the Trinity Model [26], Illness Beliefs Model [27] and the Family Resiliency Model of Family Stress, Adjustment and Adaptation [28]. A widely used model to assess the impact of a cancer diagnosis on a family is Olson's Circumplex Model [29-32]. Olson's model consists of three central components that underlie family interactions: adaptability, cohesion and communication [29].

### Adaptability

Family adaptation is the amount of change in leadership and roles that results when disruption occurs [29]. Highly adaptable families are able to quickly organise support and reorganise family roles and responsibilities. Adaptability has been linked to positive functioning in siblings [31].

However, if high adaptability is required over an extended period of time these benefits may not be sustained. A sibling's sense of security, support, and stability may be negatively impacted if they are required to continually adapt to unpredictable change [11].

### Cohesion

Family cohesion is defined as the balance between family members' independence and their togetherness [30]. Family cohesion exists on a continuum from relationships where there is minimal closeness and high levels of independence through to relationships where there is very high closeness and high levels of dependency. Research suggests that in times of major stress, it is possible for families to function at the extremes of the continuum, without harmful effects [30].

In general, high levels of family cohesion have shown to be beneficial for siblings with reports of fewer behavioural problems and less family conflict [24]. However, siblings in families with close relationships may be more exposed to the distress and suffering of the ill child and the distress of parents. Furthermore, siblings may be more vulnerable to separation anxiety during times when the ill child or parents are away from the home [18].

## Communication

Family communication is defined as the process of making information, ideas, thoughts and feelings known among members of a family unit [33]. Ongoing communication has the potential to support families who have a child with cancer to develop more functional levels of adaptability and cohesion. Positive communication includes open communication, active listening, self-disclosure, clarity, respect and regard.

Open communication between parents and siblings can ensure that siblings are kept informed and have a clear understanding of what is happening and what may happen to the ill child. Good interfamilial communication can help to reduce sibling's anxiety, maintain family relationships and help siblings cope better [2, 14, 16, 34]. In the absence of open communication siblings may experience feelings of loneliness, isolation and insecurity, and they may think that cancer is too threatening to talk about [14].

## Assessing family risk and protective factors

A family's strengths, the amount of support available to them, and potential stressors the family may be experiencing will impact on a sibling's adjustment and their ability to cope with a child's cancer diagnosis. It is important for health professionals to identify potential risk and protective factors in terms of family functioning in order to recognise siblings (and families) at risk so that appropriate support can be provided.

### RISK FACTORS

**Closed communication** e.g. siblings are not kept informed and there are limited opportunities for involvement and discussion in decision-making

**Avoidance of sharing of feelings** e.g. there is an over-emphasis on positive thinking or fear that sharing feelings may upset or worry others

**Unbalanced cohesion** e.g. families may have extreme amounts of emotional closeness and may be dependent and reactive to each other, relying heavily on each other for support

**Low levels of adaptability** e.g. inability or delay in adjusting to the situation

**Continual adaption** e.g. constant change over an extended period of time can bring instability and lack of familial support [24]

**Lack of a social support network** e.g. families who are socially isolated are likely to rely heavily on immediate family members for emotional and practical support

**Parental distress** e.g. parents are unable to adjust to and cope with the cancer diagnosis of their child

**Financial instability** (existing or as a result of the cancer diagnosis) e.g. due to medical costs, time out of work, travel

**Poor parenting skills** e.g. focus on negative behaviours with little acknowledgement of positive behaviours, different discipline techniques and expectations placed on each child

**Pre-existing stressors** e.g. mental health issues, domestic violence, drug and alcohol issues or care duties of other family members

### PROTECTIVE FACTORS

**Open communication** e.g. siblings are kept informed, and there are opportunities for negotiation and open decision making

**Open expression of feelings** e.g. family members have opportunities to express feelings and feel comfortable doing so

**Balanced cohesion** e.g. family members remain close to each other, but also maintain their own independence

**High levels of adaptability** e.g. the family is able to respond and reorganise quickly in times of stress, and have an understanding of family roles and responsibilities

**Ability to maintain a sense of normality** e.g. efforts are being made to restore normality after the initial period of change and adaptability

**Access to a social support network** e.g. have adequate support outside of the immediate family who can quickly mobilise to provide emotional and practical support

**Effective parental adjustment** e.g. parents are able to accept the cancer diagnosis and use effective coping strategies

**Financial stability** e.g. able to accommodate the financial impact associated with the cancer diagnosis

**Parenting competence** e.g. effective disciplining and monitoring of siblings, good conflict resolution skills, and reinforcement of positive behaviours for siblings

**Stable family environment** e.g. an absence of additional stressors

# TYPES OF SUPPORT

The needs of siblings are often not recognised in policy or through service delivery, despite the availability of evidence demonstrating the risk of social, behavioural and mental problems for siblings of cancer patients [35]. However, support for siblings can be provided in a number of ways at both the individual and family level.

## Information

The provision of age appropriate and accurate medical knowledge is important as it helps siblings cope with and adapt to the situation. An increase in knowledge about the illness, treatment and side effects may enhance sibling's feelings of control, helping them to feel more secure and less anxious [35].

Information should also be provided to siblings about:

- changes that may occur for them at home, and in their relationships with family, friends and peers;
- the mix of emotions they can expect to feel, and that these feelings are normal;
- positive coping strategies (e.g. ways to recognise when they are not coping and being able to let others know when they need support; having a safe place to go to get away from it all - like a friend or neighbours' house);
- support services available (e.g. CanTeen, Camp Quality, Redkite).

Information can be provided to siblings through various strategies, such as print resources (e.g. CanTeen's resource *Now What...? - Dealing with your sibling's cancer*), face-to-face (e.g. attending medical appointments, support programs, hospital tours) and websites (e.g. Now What website [www.nowwhat.org.au](http://www.nowwhat.org.au)).



## Peer support programs

Peer support programs are a common way of providing support for siblings. These programs are often delivered as camps using group peer support, although some programs facilitate individual peer-to-peer support (e.g. buddy systems). The content and length of programs can vary and may incorporate respite and recreational activities, therapeutic content or a mix of both. Outcomes achieved by evaluated peer support programs include:

- Normalisation of siblings' experience by meeting other young people who are going through a similar experience;
- Emotional and social benefits through sharing their experiences and concerns;
- Increase in self-esteem and quality of life;
- Increase in psychological adjustment and ability to cope with emotions;
- Decrease in symptoms of post traumatic stress and anxiety; and
- Increase in medical knowledge about cancer.

Peer support may also be delivered via the internet e.g. facilitated internet forums or online support groups. Family orientated peer support programs have also shown to be effective.

## Family oriented programs

Familial interventions aim to enhance protective factors such as improving communication and decreasing parental anxiety and depression. Interventions that focus on family expressiveness and support can minimise family conflict and distress, and improve the psychological adjustment of siblings [36].

Manualised interventions have been developed for health professionals to use with families such as the *Surviving Cancer Competently Intervention Program* [37] which provides health related information as well as facilitating family interactions to assist long-term adjustment.

Evidence shows that family orientated programs can help families by:

- allowing family members to gain a better understanding of their own beliefs about cancer and learn how these beliefs shape their emotions, behaviours and relationships;
- improving communication among family members, reducing distress levels, and promoting effective individual and family coping, competence, and resilience [38].

# RESOURCES AND PROGRAMS

## Camp Quality [www.campquality.org.au](http://www.campquality.org.au)

(02) 9876 0500

Camp Quality is a children's family cancer charity that is committed to bringing hope and happiness to every child living with cancer, their families and communities through ongoing quality recreational, educational, hospital and financial support programs. Camp Quality passionately believes in the power of fun in helping children and their families overcome the challenges that cancer brings.

### Resources

- Recreational Camps and Activity Days for Siblings
- Education Program for both Primary school aged children and High School
- Pilot of a Play Therapy Program at 2 Paediatric Hospitals

## CanTeen [www.canteen.org.au](http://www.canteen.org.au)

1800 226 833

CanTeen provides an Australia-wide peer support network for young people living with cancer aged 12-24 years. This includes young people who have or have had cancer and young people who have or have had an immediate family with cancer. A range of programs, recreational days and resources are offered, which provide opportunities to access information, respite, psychosocial support and peer support.

### Resources

- Recreational Days and Overnight Programs for Siblings
- Now What...? website [www.nowwhat.org.au](http://www.nowwhat.org.au)
- Now What...? Books "Dealing with your siblings cancer" and "Living with the death of your parent or brother or sister from cancer"
- It's Like This... How young people and their parents deal with cancer (DVD) - A joint resource developed by CanTeen and Redkite

## Redkite [www.redkite.org.au](http://www.redkite.org.au)

1300 722 644 or [support@redkite.org.au](mailto:support@redkite.org.au)

Redkite supports children, young people aged up to 24, and their families, by providing real and practical support throughout the cancer journey. Redkite's services include emotional, financial and educational support.

### Resources

- Telephone and email counselling
- Education grants for students whose education has been disrupted as a result of a sibling's cancer treatment
- Financial assistance to cover costs like a sibling's childcare or school uniforms
- Funding for music therapists and social workers in hospitals to support siblings as well as the young person undergoing treatment
- Book Club - Siblings can borrow books specifically written to support those going through a brother or sister's cancer

## Ronald McDonald House Charities

[www.rmhc.org.au](http://www.rmhc.org.au)

1300 307 642

Ronald McDonald House Charities has a variety of programs that provide vital support for families with a sick child.

### Resources

- Ronald McDonald Houses - offer a 'home-away-from-home' for seriously ill children and their families. These houses are attached to major women and children's hospitals
- Family Rooms – offer a comfortable retreat for parents and families of children having day treatment at a hospital, and for families with children undergoing longer-term treatment who live close to the hospital. Family rooms are a place to have a break, cook a meal, relax and unwind
- Family Retreats - offer a place for families with a seriously ill child to enjoy a holiday together, take a break from the stresses of hospital and deal with their new life situation

## Starlight Children's Foundation

[www.starlight.org.au](http://www.starlight.org.au)

1300 727 827

The Starlight Children's Foundation takes a family centred approach in providing a range of hospital, community, and outreach services aimed at improving the quality of life for children and young people with a serious or chronic illness.

### Resources

- Hospital based arts and entertainment programs, such as the Starlight Express Rooms and Starlight Fun Centres
- Adolescent online community: [www.livewire.org.au](http://www.livewire.org.au)
- Wish granting - provide the opportunity to bring the family together to share a special, once-in-a-lifetime experience. Health professionals can complete referrals at <http://www.starlight.org.au/OurPrograms/Pages/StarlightWishes>
- For more information on all other programs see: <http://www.starlight.org.au/OurPrograms/Pages/default.aspx>

**A full list of resources and references can be found on the CanTeen website [www.canteen.org.au](http://www.canteen.org.au).**

# PRACTICE IMPLICATIONS

Health care professionals involved in the care of young cancer patients are well positioned to address the needs of siblings and ensure the well-being of the whole family. The following practice implications have been drawn from the literature reviewed for this paper and include recommendations adapted from the International Society of Paediatric Oncology guidelines (SIOP) [16].

## Organisational considerations

- **Include siblings in the definition of family and ensure policies reflect the importance of including siblings in the organisation's commitment to enhance the patient's and family's wellbeing** (refer *SIOP Guidelines [16]* and *Clinical Oncological Society of Australia (COSA) Psychosocial Management of AYAs diagnosed with cancer: Guidance for Health Professionals*) [40].
- **Develop training and resources for health professionals** working with siblings to increase staff awareness of the issues facing siblings and their families.
- **Develop good referral networks for siblings**, including cancer support services and mainstream providers.
- **Offer support or referrals which address siblings' needs** for information, emotional and practical support (particularly if in a caring role).

## Working with siblings

- **Be approachable and accessible for siblings** e.g. encourage parents to bring siblings to appointments (if the patient consents and siblings are willing). Ask the sibling how they are going, normalise their experience, express an interest in the sibling's interests, and encourage them to ask questions.
- **Include siblings in discussions about the diagnosis** and keep them informed about what is happening and what may happen to the ill child e.g. effects for the ill child such as hair loss, weight gain, and fatigue.
- **Conduct individual psychosocial assessments of siblings at regular intervals.**
- **Suggest ways that siblings can be involved in the cancer journey** from the beginning e.g. visiting the ill child in hospital and maintaining regular contact. This can help to demystify the illness and treatments, and maintain sibling relationships.
- **Provide siblings with the choice of how fully and actively they would like to participate**, whilst also acknowledging the need for patient consent.
- **Use inclusive and age appropriate language** when speaking with siblings. Be aware of siblings' social, emotional, and cognitive capacity.
- **Decrease siblings feelings of guilt** by letting them know they are not responsible for causing the cancer and that it is okay to still have fun.

- **Provide siblings with resources** e.g. Now What...? print resources and website.
- **Provide siblings with realistic hope** by keeping siblings informed of the prognosis in an age appropriate manner and, where possible, emphasise the positive and optimistic side of treatment.
- **Offer tours of the hospital ward to siblings** to help them become familiar with the hospital environment and provide opportunities for questions.
- **Run programs specifically for siblings or provide information about support services available** to siblings and make referrals as appropriate e.g. CanTeen, Camp Quality, Redkite, and counselling.
- **Acknowledge and understand the range of coping strategies used by AYAs**, including crying, anger, denial, selective silence, information seeking, rebelliousness, withdrawal, writing a journal, relaxation techniques. Appreciate that what works for one child may be different to what works for another child.
- **Encourage siblings to maintain routine daily activities** such as school, sport, music, homework and relationships with friends and extended family.
- **Encourage siblings to consider whether and how much** they want to be included during the palliative phase - depending on their age.

## Working with the family

- **Acknowledge the important role of all family members** in the care of the ill child.
- **Facilitate open communication among all family members** and support parents to communicate with siblings e.g. asking sibling's how they are feeling, actively listening, and acknowledging and respecting their feelings and concerns.
- **Include sibling reports when assessing the family's psychosocial risk and adaptation.** Explore and consider the family's strengths, structure, resources, cultural values, traditions, communication dynamics and support systems.
- **Work with the family to foster more effective coping strategies** e.g. family members need opportunities to discuss what is on their mind, to share how they are feeling, and to ask questions. This may be within the family context or through the use of external supports, depending on the family's dynamics and communication styles.
- **Assist the family to return to their family routines**, while recognising that life has changed for them all as a result of their cancer experience.

## Working with parents

- **Provide support and psycho-education to parents** through one-on-one sessions or parent support groups in order to assist parents with ways to provide siblings with emotional support e.g. through active listening, normalising siblings' feelings and behaviour, and keeping siblings informed in an age-appropriate way.
- **Draw parents' attention to the common concerns that siblings might have** e.g. concern they may catch the cancer or that they caused the cancer, or fear that their sibling may die.
- **Increase parents' awareness of the needs of siblings** e.g. for attention and acknowledgement, information, to feel included, to deal with their feelings, to participate in their regular activities, and opportunities for time out.
- **Encourage parents to take time out for their own self care** as parental distress can impact siblings.
- **Help parents to understand 'normal' and acceptable adolescent coping behaviours** used during times of stress, help them to set appropriate limits for siblings, and to know how to redirect siblings to use more positive coping strategies (e.g. that it is ok to feel angry, but there are ways of expressing this anger constructively).
- **Work with parents to develop ways to keep family life as normal as possible** (e.g. balancing the needs of each child, using support networks to help maintain daily routines for siblings, and spending quality one-on-one time with each child).
- **Suggest to parents that siblings should try and connect with another adult** e.g. relative or neighbour, who they can get support from if parents are frequently absent.
- **Encourage parents to keep the school informed of the situation** (if the sibling is of school-age) and ask the school to identify a person to whom the sibling can turn to for help. The school may also be able to provide assistance with homework, assignment extensions and extra time during exams, and counselling.
- **Encourage parents to consider whether the extra responsibilities being undertaken by siblings are appropriate** and assist parents with accessing practical support to reduce the burden.
- **Provide parents with information about financial assistance they may be able to access** e.g. Government benefits or support from not-for-profit organisations such as Redkite.

## DISCUSSION QUESTIONS

1. What are you (or your organisation) already doing well to support siblings?
2. Identify two ways you could improve the support you provide to siblings.
3. Some professionals or organisations do not have the capacity to work directly with siblings. If this is the case how can you strengthen the family environment through your work with the young person with cancer and their parents?
4. What are some of the ways that you could incorporate the practice implications of this paper into your programs/practice/organisation?

**CanTeen welcomes feedback on this paper**  
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