Supporting mental health, resilience and wellbeing in families experiencing a childhood chronic illness: A synthesis of evidence to support the Childhood Illness Resilience Program.

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KEY MESSAGES

- A number of studies that focus on supporting mental health, resilience and wellbeing in families experiencing a childhood chronic illness address parent strategies to improve their own mental wellbeing but fewer studies address how parents can help their children.

- The highest quality evidence that a program is effective comes from randomised controlled trials (RCTS) from which policy makers and service providers can rely on as having least bias. There were few RCTs identified in this review, hence strong evidence in this area is lacking.

- Cross-sectional and qualitative studies provide evidence for associations, not causality. In this review, a number of factors were commonly associated with better mental health and could be incorporated into interventions.

- Below we summarise recommendations for health promotion interventions for the three areas of interest: the wellbeing of parents of children with a chronic illness, their child with a chronic illness, and the child’s siblings.

Recommended strategies for parents to enhance their own wellbeing:

- Parents should maintain normal routines and ensure enough time for their own rest and relaxation.

- Positive coping strategies should be offered to parents that encompass open communication between partners, acceptance that the cause of the illness is unknown, having a sound understanding of their child’s illness and being mentally prepared for it, and problem solving techniques.

- Good family cohesion and family/spousal functioning is associated with positive parent mental wellbeing, as is father involvement in caring for the ill child. Health promotion interventions should therefore target the whole family rather than mothers only.

- Instrumental support (e.g. having others to look after children or help with household chores) is associated with good adaption.

- Social support is largely beneficial. Too much or negative social support however, is associated with increased stress. Strategies to limit overwhelming support (e.g. taking phone off the hook, setting ‘visiting hours’ at home) may reduce parental distress.

Recommended strategies for parents to enhance their child’s wellbeing:

- Maintain a sense of normal family life and functioning by keeping to routines and activities.

- Encourage children to take an active role in managing their illness and provide them with age-appropriate information about their condition. This could be done with support from the medical team.

- Give children opportunities to meet and interact with peers who also have a chronic illness (e.g. through camps).

- Ask children what they think and feel about their diagnosis, and encourage them to voice any fears or worries.

- Seek out relaxing activities and pleasant events for children to promote positive feelings and build confidence.

- Recognise if you are highly stressed and seek support, either from a health professional or informally through family/friends. This will also help your child and their siblings.

Recommended strategies for parents to enhance sibling wellbeing:

- Let siblings help with small tasks around the house and in the care of the sick child, so they feel included and useful.

- Try to spend time with the well sibling e.g. by still dropping them off at activities, and encourage them to ask questions about their brother or sister’s illness and what they think and feel about the diagnosis.

- Give siblings opportunities to meet and interact with peers who also have a sibling with a chronic illness (e.g. through camps).

- Be open and honest with siblings about the illness.
- Ensure siblings keep up with friends as they are a valued source of social support.

**Recommended strategies for children to enhance their own wellbeing**

- Spend time with friends and peers.
- Engage in enjoyable activities like hobbies or sports.
- Attend illness-related camps.
- Talk about the illness and related thoughts and feelings with trusted adults and friends.
- Spend time with role models and mentors such as a special relative or family friend.

**EXECUTIVE SUMMARY**

**Context**

In addition to the physiological and medical burden associated with managing a childhood chronic illness, families experience a multitude of stressors and psychosocial difficulties that can affect relationships, education and employment. The mental wellbeing of families experiencing childhood chronic illness is also a cornerstone of effective medical outcomes. Adherence to medical regimens, attendance at medical appointments and effective medical decisions can be compromised when the mental wellbeing of families experiencing childhood chronic illness is suboptimal. Improvements to mental wellbeing of family members can therefore improve medical outcomes for children with a chronic illness.

In light of this, an essential component of the management of the child’s chronic health condition relies on enhancing and maintaining the mental wellbeing of parents, the child/adolescent with a chronic illness and their siblings. Many approaches to the management of childhood chronic illnesses however, remain reactive, focusing primarily on families faring poorly from a mental health perspective. Mental resilience refers to those families who manage to cope well, from a mental health perspective, despite the difficulties associated with their child’s illness. Building our understanding of the strategies parents and children use to enhance mental wellbeing is a useful paradigm for successful intervention; i.e. those attributes and strategies associated with mental wellbeing among families experiencing childhood chronic illness provide the best targets for intervention.

The purpose of this literature review is to identify and synthesise current literature to inform a health promotion intervention, entitled the Childhood Illness Resilience Program (ChIRP), which aims to support mental health, resilience and wellbeing among children/adolescents with a chronic illness, their parents and siblings. Specifically, in the context of childhood chronic illness, this review aims to identify evidence-based strategies parents can use to a) enhance their own mental wellbeing and relationship with their partner and b) their child/ren’s mental wellbeing and also c) strategies children with a chronic illness and their sibling/s can use to enhance their own mental wellbeing.

**Approach**

We sought to identify and synthesise results from systematic and other reviews, randomised controlled trials and other intervention studies, longitudinal studies, cross-sectional studies and qualitative studies. Published studies that met the inclusion and exclusion criteria were identified from a variety of sources including standard clinical databases (Medline, PsychInfo and Cinahl), published systematic reviews and hand searching of key articles. We also consulted with a number of experts at the Royal Children’s Hospital (RCH), Melbourne and searched a number of websites identified by clinical staff or cited in articles identified during the review.
Inclusion criteria for studies were a) studies with a child aged 0-18 years with a chronic illness including but not limited to asthma, cancer, cystic fibrosis, dermatitis (eczema) and type-1 diabetes, b) outcomes of behavioural, emotional or social problems assessed by standard measures, and c) published between 1996 and 2011. Exclusion criteria were Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, child abuse, traumatic event (non-medical/surgical), case studies and studies reported in a language other than English.

Results

Thirty six studies assessed parent strategies to enhance their own mental wellbeing. Results revealed that specific coping strategies, (e.g. open communication between partners, acceptance that the cause of the illness is unknown, searching for religious meaning to the disease), good social support, frequent use of problem solving and emotional regulation strategies, greater paternal involvement, good family cohesion and family functioning, and positive spousal relationships were associated with positive parental mental wellbeing. In the qualitative and web-based literature, specific strategies identified to promote positive parent mental wellbeing included maintaining normalcy, engaging in ‘self-care’ activities (e.g. enjoyable activities/hobbies), good nutrition, regular exercise and confrontation and acceptance of the disease.

A small number of interventions were located with mixed results. There was limited support for the role of psychoeducational interventions (e.g. information resources, problem solving and stress reduction strategies) in promoting positive parent mental wellbeing. Other behavioural (e.g. relaxation, yoga), cognitive-behavioural (e.g. changing beliefs about the illness and anticipating treatment) and peer support (e.g. telephone peer support) interventions however, improved parent mental wellbeing. It is worth noting however, that while good social support received significant empirical attention in the context of chronic childhood illness, evidence from longitudinal studies highlighted that the nature and ‘dosage’ of social support is also very important; too much social support for instance (e.g. constant phone calls) was perceived as overwhelming and distressing for some parents.

Fifteen studies assessed the role of parent strategies in positive child mental wellbeing. Results revealed that maintaining daily routine and structure, parent-led relaxation/distraction strategies including provision of physical activity and yoga for the child, provision of disease-related information, allowing child self-management of medication (for older children), less overprotective parenting, actively managing own parental distress, social support for the child, positive maternal communication and family environment were all associated with positive child mental wellbeing. Intervention studies suggest that children can assist their own mental wellbeing by engaging in stress reduction strategies (such as yoga and physical activity) and adopting positive coping strategies.

Six studies assessed the role of child strategies to enhance their own wellbeing. Attending group camps, open communication (e.g. informing friends of their chronic illness), relaxation and participation in physical activity (for asthma sufferers), social and peer support, distraction techniques, having a mentor/role model, group therapy and developing new interests were associated with positive child mental wellbeing.

Eighteen studies assessed the role of parent strategies to enhance sibling mental wellbeing. Parental provision of age-appropriate medical information regarding the ill sibling, emotional support and validation (both in conjunction with and independently from the ill child), maintaining daily routines, equitable parenting (between the ill child and the sibling), access to social support (e.g. sibling support group camps) as well as positive and open family
communication (including enabling the sibling to participate in the care of the ill child) were all associated with positive sibling mental wellbeing.

- **Factors that enabled or facilitated adoption of strategies to enhance parent, child and sibling mental wellbeing** included good social support, similar coping and communication styles between spouses and good communication with medical professionals. Factors associated with better parent mental wellbeing included higher income, higher education levels, and family centred service provision.

- **Factors that acted as barriers to the implementation of strategies to enhance parental wellbeing** included role strain, poor satisfaction with basic needs, spousal differences in or less useful communication styles/coping strategies, less optimism, neglecting own health, passive avoidance (e.g. smoking, alcohol consumption), cognitive avoidance and poor expression of emotion. Several sociodemographic and family characteristics were also associated with poorer engagement and uptake of strategies to improve mental wellbeing. These included: race (being Black), low socio-economic position (SEP), financial problems, family stress, poor family functioning, marital conflict, and being single and young parents.

**Conclusions**

In the context of childhood chronic illness, positive parental mental wellbeing is a function of good social support and family/spousal functioning, use of effective cognitive coping strategies, maintaining normal routines and ensuring time for rest and relaxation. Child mental wellbeing is associated with positive parenting and parent-child communication, parental facilitation of independence for older children and children’s own engagement in relaxation activities. Inclusion of siblings in distribution and discussion of medical information, as well as access to social and emotional support and validation were pivotal in maximising sibling mental wellbeing.
Supporting mental health, resilience and wellbeing in families experiencing a childhood chronic illness: A synthesis of current evidence.

1. CONTEXT

Childhood chronic illness affects up to around 15% of Australian families (http://www.aihw.gov.au). With increasing survival estimates, coupled with lengthy treatment regimes and associated effects, long-term management of childhood chronic illnesses has become an important focus. In addition to the physiological and medical burden, families experience a multitude of stressors and psychosocial difficulties associated with caring for a child with a chronic illness.

Parents in particular have increased responsibility for the management of their child’s chronic illness, and as such are critical members of the child’s health care team. Parents take on a new role where typical caregiving tasks, including meeting the physical and emotional needs of family members, managing household, educational and work duties, are accompanied by additional demands attributed to the childhood illness. These include, carrying out medical regimens, making medical decisions, understanding and negotiating the medical system, and heightened obligations of protection and emotional support for their partner and children. As a result, parents with chronically ill children are more likely than other parents to experience poor mental wellbeing with psychological symptoms such as anxiety and depression.

Children and adolescents with a chronic illness also experience a heavy psychosocial toll and are more likely than other children to develop social or emotional problems that can continue into adulthood. For instance, children can experience isolation from their sibling/s, friends and peers, low self-esteem, adjustment and behavioural problems as well as symptoms of stress, anxiety and depression. Siblings of the ill child can have negative feelings such as resentment and guilt, which may affect their psychosocial wellbeing and behaviour.

The psychosocial stressors experienced by families with a child with a chronic illness can affect other long-term life outcomes, such as relationships, education and employment. The mental wellbeing of families experiencing childhood chronic illness is also a cornerstone of effective medical outcomes. Improvements to mental wellbeing of family members can therefore improve medical outcomes for children with a chronic illness.

In light of this, an essential component of the management of the child’s chronic health condition relies on enhancing and maintaining the mental wellbeing of parents, the child/adolescent with a chronic illness, and their siblings. Mental resilience is a dynamic process encompassing positive psychosocial adaptation within the context of significant adversity. In the context of chronic childhood illness, mental resilience refers to those families who manage to cope well, from a mental health perspective, despite the difficulties associated with their child’s illness.

The purpose of this literature review is to identify and synthesise current literature to inform a health promotion intervention, entitled the Childhood Illness Resilience Program (ChIRP), which aims to support mental health, resilience and wellbeing among children/adolescents with a chronic illness, their parents and siblings.

Specifically, in the context of childhood chronic illness, this review aims to identify evidence-based:
- Strategies parents use to enhance their own mental wellbeing and relationship with their partner;
Strategies parents use to enhance their child/ren’s mental wellbeing;  
Strategies children with a chronic illness and their sibling/s use to enhance their own mental wellbeing; and  
Enablers and barriers to implementation of strategies used by families experiencing childhood chronic illness to enhance their mental wellbeing.

2. DEFINITIONS and CONCEPTS

Mental and Psychosocial Wellbeing

Mental and psychosocial wellbeing are terms often used interchangeably throughout the literature yet are defined as slightly different concepts. Mental wellbeing, also referred to as mental health, is defined by the World Health Organization (WHO) as a state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community. In addition to the WHO definition, health professionals and researchers often define mental health as the absence of clinically defined psychological conditions such as depression, anxiety and post-traumatic stress. Psychosocial wellbeing extends the definition of mental wellbeing to include social networks, resources and supports. Specifically, the term ‘psycho-social’ denotes the inter-connection between psychological and social processes and the fact that each continually interacts with and influences the other. Throughout this report, the term mental wellbeing is primarily adopted, as it is the ‘psychological’ wellbeing of families experiencing a childhood chronic illness that is of main interest.

Coping

Coping, specifically psychological coping, is defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” [1]. In the context of childhood chronic illness, coping is most often operationalised as the ‘coping mechanisms’ or ‘coping styles’ employed by the individual in response to the illness. The most common typology of coping style includes ‘active behavioural’ or problem-focused coping (which includes information seeking and problem solving), ‘active cognitive’ or emotion-focused coping (which involves expressing emotion and regulating emotions), and avoidance coping (which involves avoiding the problem) [1]. More specific examples in the context of childhood chronic illness include: problem-focused coping (e.g. facing the problem/stressor and seeking solutions), social support seeking (see definition of social support below), emotion-focussed (e.g. minimisation and avoidance of the disease) and depressive coping (e.g. asking ‘Why me?’), cognitive coping (e.g. reframing the situation to cope with the stressor, such as looking for the positive in what is happening), compliance coping (trust in treatment) and self encouragement coping (convincing oneself of treatment success).

Support

The concept of support frequently appeared in the review of the literature. Social support was the most prevalent form, but other types of support such as instrumental support (e.g making family meals) were also reported. In general, social support can be defined as a relationship with others characterised by feelings of love, empathy, belonging, understanding, and more literally being there to provide assistance if/when required [2, 3]. Instrumental support included more practical and physical forms of assistance such as financial assistance, meals, respite, and looking after
children when necessary [3-8]. Other types of support included informational support (e.g. giving advice or directives), and emotional support (e.g. love and acceptance) [3, 7]. Sources of support included family, friends, neighbours, workplaces, churches, medical staff and the wider community [2, 4-8]. Some studies looked at the associations with support and its intensity or availability to parents, children and siblings. In some studies, social support was reported as a moderating or mediating variable on outcomes such as marital satisfaction and health-related quality of life [6, 8, 10]. Other studies used measures of coping styles which included social support as a category or specific coping style (e.g. social support seeking) [11].

3. APPROACH

We sought to identify and synthesise results from systematic and other reviews, randomised controlled trials, longitudinal studies, cross-sectional studies and qualitative studies. Published studies that met the inclusion and exclusion criteria outlined below were identified from a variety of sources including standard clinical databases, published systematic reviews and hand searching of key articles. Below is a brief summary of the inclusion and exclusion criteria, and search strategies used to identify the studies.

**Inclusion and exclusion criteria**

The following studies were included:

- Systematic reviews, randomised controlled trials, longitudinal studies, cross-sectional studies and qualitative studies.
- Studies with a child aged 0-18 years with a chronic illness including but not limited to asthma, cancer, cystic fibrosis, dermatitis, eczema and type-1 diabetes.
- Outcomes of behavioural, emotional or social problems assessed by standard measures.

The following studies were excluded:

- Studies with a child with Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, child abuse, traumatic event (non-medical/surgical);
- Case studies; and
- Studies reported in a language other than English.

**Identification of studies**

1) For this review, we identified studies meeting the inclusion and exclusion criteria in a search of published abstracts in the databases of Medline, PsychInfo and Cinahl from 1996-2011. Key Medical Subject Headings (MeSH terms) used in the search were Populations: "parents" “siblings” “caregivers”, "infant (1 to 23 months)", "preschool child (2 to 5 years)", "child (6 to 12 years)" “adolescent (13-18 years)”

2) Illnesses: asthma, chronic illness, cystic fibrosis, diabetes, dermatitis, neoplasms,

3) Outcomes: Adjustment, Adaptation, psychological, Anxiety, Coping, Family relations, Major depression, Parenting, Psychosocial support, Resilience, Self efficacy, Social Support

Abstracts were reviewed and papers were accessed if they (a) met the inclusion criteria and (b) addressed one of the four review aims. A search of websites identified in the literature to support children with chronic illness and their families were also reviewed.
4. RESULTS

4.1 PARENT STRATEGIES TO ENHANCE OWN WELLBEING

Results from Reviews

Five reviews looked at parent strategies to enhance their own wellbeing. Four of these reviews focused on cancer, the other was a review of psychological interventions in children and adults with cystic fibrosis. The number of studies in each review ranged from 11 to 54 with a variety of methodologies including a meta-analysis, Cochrane review, randomised controlled trials and qualitative studies.

A 2010 review of psychological interventions highlighted that stress reduction and coping strategies appeared most effective in improving mental health and coping outcomes among parents of children with cancer [12]. Interventions in this review were mainly randomised controlled trials (7/11) and included a variety of intervention approaches such as, web-based information, guided written disclosure, group and individual approaches. Although there was limited consistency in findings, recognising and validating parent’s feelings of anxiety, depression and stress appear most effective in improving coping outcomes.

Glascoe and Quittner [13] conducted a Cochrane review of psychological interventions with parents of children with cystic fibrosis. The review included 13 randomised controlled trials representing data from 529 participants. Studies mainly assessed behavioural and educational interventions. Results from this review highlighted strategies for both parents and the child that can improve parent mental wellbeing, namely anxiety and mood. These included: massage (mother to child), music therapy (in mothers and infants to improve enjoyment and positive experiences of physiotherapy used with infants), and biofeedback treatments (for both parents and the ill child). There was no clear evidence however as to which was the most effective psychological treatment.

da Silva Pedro and colleagues [14] provided an overview of the evidence base for the role of social support to families of children with cancer. In total, 15 studies were reviewed including quantitative and qualitative methodological approaches, two experience reports and three literature reviews. The review reported on the identification of three themes: (i) social support and the trajectory of cancer, (ii) social support to healthy siblings and (iii) social support to fathers and mothers. This review underscores the importance of social support for families of children with cancer. Sources of support included partners, family, friends, employees, hospital team and other parents experiencing the same situation. Several strategies to increase social support were reviewed (discussed in more detail in Section 4.3).

Two reviews focused on use of strategies, psychological adjustment and coping experiences of parents of children with cancer. One study was a systematic review (54 cross-sectional and longitudinal papers) of factors specifically related to parental health and wellbeing [10]. Family cohesion and effective stress management were associated with better parent psychological health. Grootenhuis and Last [15] reviewed 84 papers that included a small focus on factors that influence parental adjustment to cancer. Excluding illness and demographic variables, specific coping strategies, such as open communication, acceptance that the cause of the illness is unknown, acceptance of medical advice and seeking social support were all associated with positive parental adjustment.
Results from Intervention Studies

Of the nine interventions studies, six were from the US with the remaining three from Iceland, Canada and Germany. All intervention studies investigated different chronic illnesses including type-1 diabetes (n = 4), cancer (n = 2), cystic fibrosis (n = 1) and a combination of chronic illness (n = 2).

Sample sizes were generally small (<35), however two studies had samples over 100 [16, 17]. Approximately half of the intervention studies had a control group; the others were quasi-experimental in design. Interventions were psycho-educational, cognitive-behavioural, behavioural or social support based.

Psychoeducation Interventions

Psychoeducational interventions were group or individually based. Group interventions targeted illness uncertainty, illness management (e.g. information resources, problem-solving techniques) and coping skills techniques (e.g. stress management, communication skills). One RCT [16] reported significant improvements in parent quality of life and coping following a psycho-educational intervention however, no group differences were observed (i.e. these improvements were also observed for an ‘insulin regimen group’ that focused on carbohydrate counting, managing sick days, intake and insulin adjustments for sports). Further, no improvements in family conflict were observed for either group [16]. In another study [18], intervention mothers, but not fathers, reported reduced stress and a reduction in child behaviour problems following a psycho-educational group intervention. A short term educational and support intervention [19], yielded limited results other than that mothers and fathers found the information helpful. An education support intervention had limited impact on parental mental health for families with a child with cystic fibrosis. Goldbeck and Babka [20] found no changes in family cohesion and optimism, maintaining social support, self-esteem and psychological stability, following a psycho-educational family intervention.

Another psychoeducational intervention was telephone-based and incorporated psychosocial factors influencing engagement in health behaviours e.g. increasing support and efficacy for diabetes management tasks, promoting mastery learning through skills training such as problem-solving and encouraging use of cognitive-behavioural coping strategies [21]. Parents who received this intervention reported decreases in stress but not depression and anxiety or perceived social support compared to controls.

Cognitive-behavioural family interventions:

One study implemented a cognitive-behavioural family intervention for parents experiencing childhood cancer that focussed on understanding beliefs about cancer/cancer treatment and
anticipating its impact [22]. Compared to controls, intervention parents had reduced anxiety and post-traumatic stress symptoms, suggesting the potential beneficial role that having a sound understanding of their child’s cancer and being mentally prepared for its impact can have on parent mental wellbeing.

**Behavioural Relaxation interventions**

Results regarding the use of relaxation techniques in improving parent mental wellbeing are mixed. A study that assessed a single tailored yoga session consisting of seated meditation and traditional yoga poses with relaxation music, resulted in reduced anxiety and stress (quantitatively measured), increased relaxation, and improved mother-child bonding (qualitatively measured) [23]. Self-guided imagery relaxation techniques were used in another study with parents with a child with a chronic illness in an attempt to reduce anxiety. Although caregivers reported using the relaxation techniques more than twice daily, there were no differences between the intervention and control groups in anxiety [24].

**Peer support intervention**

One intervention assessed the impact of a telephone peer support group on qualitative changes to parent wellbeing [17]. Parents described increased social support, enhanced coping, increased sense of confidence, changed outlook, change in family activities, relationships, and health care encounters.

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**Summary of Evidence from Intervention Studies**

for parent strategies to enhance own wellbeing

- Cognitive-behavioural, behavioural (relaxation) and peer support interventions may improve parent mental wellbeing.
- Psychoeducational interventions are less effective in improving parent mental wellbeing and for parents of children with type-1 diabetes, are no more effective than illness management resources.
- Coping skills techniques, yoga and peer support interventions appear most beneficial in improving parent mental wellbeing.

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**Results from Longitudinal Studies**

Seven longitudinal studies were identified. Two were from the Netherlands with the remaining five from the US, UK, Iceland, Germany and Sweden. All longitudinal studies were conducted with families experiencing childhood cancer, with one study [25] including families with children with a variety of illnesses. Sample sizes ranged from 100-200.

**Problem solving skills, family cohesion, strain, self efficacy and coping.**

Three longitudinal studies focussed on factors that reduced mental wellbeing among parents rather than strategies that enhanced mental wellbeing. One study highlighted that parents who avoided stimuli that may elicit traumatic memories or emotions were more at risk of developing post-traumatic stress [26]. Further, mothers with poorer problem solving skills (e.g. carelessness, greater impulsivity and avoidance style) were more likely to have increased negative affectivity and post-traumatic stress symptoms [27]. In another study, low levels of family cohesion, self-reported strain, and low efficacy predicted *maternal* distress, while perceived employment
problems, self-reported strain, and low parenting efficacy predicted paternall distress [28]. For both parents, self-directed coping (e.g. self-blame) predicted distress. Strategies that incorporate family communication, positive coping techniques and support methods may improve parent wellbeing.

**Social Support**

In another longitudinal study, the absence of social support was not a significant predictor of parental distress or post-traumatic stress symptoms [25]. Only disease-specific factors, particularly, the amount of daily care associated with the disease, predicted parental distress and post-traumatic stress symptoms. The longitudinal role of social support in predicting parent mental wellbeing was also examined by Wijnberg-Williams and colleagues [29]. From the three aspects of social support measured (frequency of supportive interactions, frequency of negative interactions, and amount of dissatisfaction with support), negative interactions and dissatisfaction with support predicted higher psychological distress for fathers only. Social support did not significantly predict maternal psychological distress. Hoekstra-Weebers and colleagues [30] found that dissatisfaction with social support predicted parent psychological distress and negative interactions predicted psychological distress for fathers only. Negative interactions included fathers’ perceptions that others’ took their feelings lightly, lost his or her temper with them, or tried to get them to do something they did not want to do. The authors also found a positive association between the number of supportive social interactions and parent distress, that is, too much social support increased parental distress, possibly because it was overwhelming. In contrast, Goldbeck [31] highlighted that seeking social support (as defined as an attentive, active communication coping style) and religious strategies (defined as a religious attitude and a search for a religious meaning of the disease) predicted better parental quality of life. These results suggest that while the act of seeking social support may serve as a coping mechanism that may assist parental mental wellbeing, the impact of social support itself varies. Negative encounters of social support and either too little or too much social support predict parent mental distress, underscoring the need for parents to have positive interactions and supports and avoid people with whom they experience negative interactions.

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<tr>
<th>Summary of Evidence from Longitudinal Studies for parent strategies to enhance own wellbeing</th>
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<tr>
<td>• Poor problem solving skills, poor family cohesion, low self efficacy, self-directed coping, perceived strain and negative encounters of social support predict poor parental mental wellbeing.</td>
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<tr>
<td>• Avoiding facing the illness is associated with poorer parental wellbeing so families should be encouraged to accept their child’s illness.</td>
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<td>• Fathers may be especially affected by negative interactions and poor social support.</td>
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<td>• Coping styles, such as seeking social support and searching for a religious meaning to the disease, predict better parental mental wellbeing.</td>
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<tr>
<td>• The impact of social support varies. Too much or negative social support is associated with increased stress. Strategies to limit overwhelming support (e.g. taking phone off the hook, setting ‘visiting hours’ at home) may reduce parental distress.</td>
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**Results from Cross-sectional Studies**

Eleven cross-sectional studies were identified. Three originated from the US, two from Canada and the remaining six from Australia, The Netherlands, Finland, Sweden, Germany and Israel. Six
studies focused on parents of children and adolescents, two studies focused solely on parents of children under 12 years, and three did not report child age. Four studies focused on parents of children with cancer, two focused on children with cystic fibrosis, two covered multiple diagnoses (including diabetes, asthma, and Down’s syndrome) and three specified only ‘chronic illness’. One study focused solely on mothers.

Six studies reported associations between coping styles and wellbeing [33-35, 37, 39]. One study found the more frequent use of social support/advice seeking predicted a decrease in anxiety symptoms [33]. Similar decreases in anxiety and also depressive and post-traumatic symptoms were predicted by the more frequent use of a cognitive problem appraisal strategy [33]. Problem appraisal strategies included religious coping/optimism [33]. In contrast, symptoms increased as a function of using problem-solving strategies (attempting to manage the event), avoidant coping (e.g. substance use), and negative self-blame more frequently [33]. Anxiety symptoms also increased as a function of using active coping strategies which was speculated to stem from ‘confronting the stressor’ [33].

A second study that focused on similar measures of wellbeing found more frequent use of active-problem focusing (acting immediately and being goal-oriented, sorting things out), and less use of other coping styles (e.g. avoidance behaviour, passive reactions - isolating from others, escaping into fantasies) was associated with less anxiety and depression [38]. The study also found a substantial association between passive coping and increased emotional distress, with the authors suggesting that passive coping may be closely related to learned helplessness [38]. Expressing negative emotions (anger and annoyance) was related to both anxiety and depression in parents possibly because expressing negative emotions may lead to less social support [18]. Another study found that for fathers, lower family cohesion was associated with poorer adjustment while coping by understanding the child’s medical situation (e.g. asking questions of professionals/other parents) was associated with better adjustment [35]. Similar results were reported by three other studies that found associations between avoiding the situation and/or self-blame and increased depressive and anxious symptoms [34, 37, 39]. Overall, studies suggest that confronting the stressor as opposed to avoiding it, is generally associated with better wellbeing, although there are exceptions.

A third study also found that coping styles of ‘control of emotions/retreating from social situations’ (e.g. “I tried to keep my feelings to myself”) and ‘depressive coping’ (e.g. “I asked myself again and again why me?”) were associated with poorer health related quality of life [38]. In contrast, coping styles of ‘compliance/trust in treatment’ (e.g. “I did exactly what my doctor advised me to do”) and ‘self encouragement’ (“I was convinced that treatment would be successful”) were associated with better health related quality of life. The size of effects of these factors for parent wellbeing was generally quite small [33-35, 37, 39].

Three studies examined family dynamics in relation to parental wellbeing [9, 32, 36]. One study found that greater paternal involvement was associated with fewer maternal psychiatric symptoms [32]. Gavin and Wysocki [32] speculated that this relationship may be bidirectional; mothers with better psychological adjustment may be better at eliciting support from their husbands. In turn, when mothers receive more support from their spouses they may experience less stress and/or distress [32]. Greater paternal involvement was also associated with reduced impact of the disease on family functioning, with the authors speculating it may buffer the effects of stress, role strain and treatment burden [32]. Another study found that maintaining and promoting the cohesiveness of the family unit helped the family members cope and adapt to the child’s chronic illness [9]. This was achieved by sharing time and experiences together and sharing daily chores [9]. Similarly, a third study found that better family functioning was associated with lower caregiver strain, better self-perception and more social support [36].
One study found that adapting well to the child’s illness by ensuring the parent’s attitude towards the chronically ill child did not differ from their attitude towards healthy children, was associated with better parent wellbeing [7]. A major part of good adaption was good relationships between family members and freedom to express feelings in the family [7]. Social support was also important [7]. Parents with high instrumental support reported fewer family conflicts, less sorrow and fear, better acceptance of the situation, and more nearness and social relationships than did parents with low instrumental support [7].

Summary of Evidence from Cross-sectional Studies for parent strategies to enhance own wellbeing

- More frequent use of emotional regulation strategies is associated with fewer depressive, posttraumatic and anxiety symptoms, except in certain cases where confronting the stressor were anxiety provoking.
- Self-blame is associated with poorer wellbeing.
- Greater paternal involvement is associated with increased maternal wellbeing and better family functioning.
- Maintaining and promoting family cohesion (e.g. maintaining normal routines, sharing experiences, sharing household chores) aids coping and adaption.
- Positive spousal relationships are associated with less depressive symptomology.
- Instrumental support (e.g. having others to look after children or help with household chores) is associated with good adaption.

Results from Qualitative studies

Seven qualitative studies were identified. Of these, three were from the US, two were from Canada, one was from Australia, and one was from The Netherlands. Four studies focused on parents of children diagnosed with cancer, two only specified ‘chronic illness’, and one study covered a number of different diagnoses (e.g. cancer, cystic fibrosis, spina bifida, developmental delay and diabetes). The majority of the studies focused on children and/or adolescents (1-18 years). Three studies focused on fathers, one on mothers, and the remaining three on both parents.

The majority of the studies focused on coping strategies parents found to be helpful. Helpful strategies included adjusting one’s perspectives and expectations, such that small achievements were celebrated as opposed to ‘giant leaps’ in development [41, 42]. This was closely connected to the idea of accepting the child’s condition, which in one study was referred to as ‘confronting the stressor’ [42, 43]. Other ways to confront stressors included seeking medical information and talking to other parents in similar situations [43]. Seeking additional medical information was also cited as a way to take control of the situation [5, 43]. This included being prepared and knowledgeable about routine medical needs [41]. Despite this, some fathers reported that they minimised knowledge-seeking behaviours, believing that increased knowledge about disease progression could increase stress and difficulties maintaining normalcy [42]. Similarly, some parents reported focusing their energy on daily activities as opposed to contemplating the future was a positive coping strategy [42].

Many parents reported maintaining normalcy to also be a positive coping strategy [5, 42]. Fathers reported engaging in distraction activities, such as sporting events, was beneficial in moving on with life, enhancing their adaption and combating stress [42]. Mothers also reported the need to have time for themselves to engage in activities or outlets that gave them a sense of enjoyment such as reading, dancing or gardening [8, 41]. This was often reported by parents who previously
had neglected their own needs in order to make sure they focused on their children [5, 41]. Both mothers and fathers reported that looking after themselves both physically and psychologically was positive and necessary for their wellbeing [5, 41]. Adopting a healthy lifestyle was cited as particularly important for fathers who believed they needed to stay healthy in order to be strong and available to support their family [8].

Ensuring communication within the family and wider community was also reported to be important [40, 41]. Maintaining open communication helped families stay connected and maintain normalcy [40]. Specific strategies included having family conferences to resolve issues and maintaining rituals by including them into other activities (e.g. saying night-time prayers at the dinner table) [40]. Despite this, some mother’s reported the need for ‘wind down’ time after work before discussing problems [40]. Other avenues for communication included developing partnerships with professionals, connecting with peers, and becoming an advocate (e.g. for child in appointments, being involved with legislative issues) [41].

<table>
<thead>
<tr>
<th>Summary of Evidence from Qualitative Studies for parent strategies to enhance own wellbeing</th>
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<tbody>
<tr>
<td>- Adjusting expectations, knowledge-seeking about the medical condition, and accepting the child’s condition were reported by parents to improve their own mental health.</td>
</tr>
<tr>
<td>- Focusing energy on daily activities was reported as a positive coping strategy for some parents.</td>
</tr>
<tr>
<td>- Maintaining normalcy where possible was reported as important for coping.</td>
</tr>
<tr>
<td>- Parents need to look after their physical and mental health, and have time for their own enjoyable activities.</td>
</tr>
<tr>
<td>- Ensuring open communication within the family and with the wider community was perceived as particularly important for coping and adaption.</td>
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</table>

4.2 PARENT STRATEGIES TO ENHANCE RELATIONSHIP WITH PARTNER

Results from Reviews, Interventional, Longitudinal and Qualitative Studies

We found no articles addressing this area.

Results from Cross-sectional Studies

Four cross-sectional studies reported strategies to enhance parent’s relationship with their partner. Three studies were from the US and the other was from Israel. One study focused solely on parents with children seven years or younger, while the other three focused on both child and adolescents. Two studies only specified the child’s diagnosis to be a ‘chronic illness’, one study focused on asthma, and one on cancer. Three studies focused on both mothers and fathers, and one mothers only.

Greater paternal involvement was associated with better marital satisfaction and family functioning [32]. Family cohesiveness, cooperation, and participation in the care of the ill child enhanced father’s marital satisfaction and involvement in the care of the ill child [9]. In contrast, the use of emotional coping behaviours was associated with a reduction in father’s marital satisfaction [9]. Similar results were found for mothers, with negative effects associated with emotional coping behaviours and a negative perception of the impact of the child’s illness [9]. Guilt feelings related to the negative perception of the child’s illness also diminished the father’s sharing of his feelings with his spouse, resulting in less marital satisfaction [9]. Good communication between spouses was associated with less depressive symptomology [45].
4.3 PARENT STRATEGIES TO ENHANCE SUPPORT NETWORKS

Results from Interventional, Longitudinal, and Qualitative Studies

We found no articles addressing this area.

Results from Reviews

One review study [14] highlighted suggestions to increase the support offered to families. Suggestions for parents were mainly centred on seeking and uptake of social support that was delivered either in hospital or electronically.

Results from Cross-sectional Studies

Only one study reported any form of strategy to enhance support networks [32]. A US study, which focused on parents of both children and adolescents with a ‘chronic illness’ found that greater paternal involvement to be related to more favourable outcomes of family functioning [32]. This included reduced impact of the disease on the family [32].

4.4 PARENT ENABLERS OF IMPLEMENTATION OF STRATEGIES

Few studies directly addressed enablers of strategies to enhance parent own wellbeing. Those that did were largely cross-sectional and qualitative studies and identified support, particularly social support, as a key enabler. Aspects of support including psychological and physical supports from phone calls, meals, financial assistance and flexible work arrangements [4, 5, 8] allowed parents to engage in strategies (eg exercise, leisure activities) to improve their own wellbeing. Fathers reported social support allowed them to stay emotionally and psychologically strong and provide basic needs for their families [4, 8]. Other benefits included reduced isolation, warding off despair, introducing new ideas and/or possibilities [8].

Support was also related to better health related quality of life and reduced traumatic stress symptoms and impact of the disease (cystic fibrosis) [6, 37, 46]. Having social support and leisure time for parents individually and as a couple was predictive of better health related quality of life [6]. Similarly, having social support, as well as using self-encouragement, having trust in treatment, and being able to express one’s emotions was associated with better health related quality of life [47]. One study also found that the more social support parents sought from family and friends, the less the emotional impact of their child’s disease [37]. Overall, support was repeatedly shown to be an important enabler of parental wellbeing.

Summary of Evidence from Cross-sectional Studies for parent strategies to enhance relationship with partner

- Greater paternal involvement is associated with better marital satisfaction and family functioning.
- Father’s marital satisfaction and involvement is enhanced via family cohesiveness, cooperation and participation in the care of the ill child.
- Emotional coping is associated with poorer maternal and paternal marital satisfaction.
- Guilt related feelings about a negative perception of the child’s illness may result in the father not sharing his feelings with his spouse, and lower martial satisfaction.
- A positive spousal relationship is associated with less depressive symptomology.
One longitudinal study conducted by Goldbeck [31] highlighted that personal quality of life increased for both parents if they used the same or similarly focused coping styles in social support seeking and religious strategies.

Spirituality was also cited as important in implementing coping strategies by some parents [4, 5]. Aspects of spirituality included returning to or adopting a new religion [4, 5] or embracing a spiritual outlook, including becoming more serene [4, 5].

Other enablers for parents included positive and good communication with their children and medical professionals, and strong family relationships [4, 5, 8].

While not strictly enablers, a number of modifiable, protective factors for parent wellbeing emerged from the literature. These included exercise, healthy eating habits, better sleep quality [36] and more days per year on family holidays [6]. Unmodifiable/partially modifiable factors associated with improved parent quality of life included higher education levels [6] and family centred care [48].

### 4.5 PARENT BARRIERS TO IMPLEMENTATION OF STRATEGIES

No studies specifically examined parent barriers to implementation of strategies to enhance parent wellbeing. Rather, the research tended to focus on parent and family factors associated with poorer parent wellbeing. Factors included role strain/burden, dissatisfaction with basic needs, use of emotion-focused coping styles, and lack of social support [8, 10, 15, 46, 49]. One study found caregivers who did not meet their basic needs were more likely to use emotion-focused coping and in turn report more depressive symptoms [49]. Similar to role strain, caregiver reports of burden of illness on family predicted more caregiver psychiatric symptoms [50]. Another study found that having different communication styles and/or coping strategies (e.g. talking about issues vs. ignoring them, being optimistic and upbeat vs. pessimistic) between parents was a barrier to positive wellbeing [5, 51]. Both passive avoidance (e.g. smoking, alcohol consumption) and cognitive avoidance (e.g. not thinking about the disease, occupying thoughts elsewhere) were also barriers to parental wellbeing [51].

One study found that for fathers, a lack of support (e.g. inflexible working conditions or social withdrawal) and/or support lessening over time was related to poorer wellbeing [8]. For mothers, low levels of social support (both instrumental and emotional) and family cohesion were associated with poorer adjustment [35]. Infrequent companionship was also reported to be associated with poorer maternal mental health and social functioning [52]. Fathers also reported that they felt isolated in their suffering by having to be strong and provide support for their family...
The gender role stereotypes they felt needed to be maintained led to stress, exhaustion, and emotional vulnerability [8]. Similarly, a parent neglecting their own health was associated with poorer parental wellbeing. This included refusing medication, not getting regular health checks and poor diet [5]. Lack of leisure time, lack of social support, financial concerns, and a perception that the child’s illness affects everyday life were also risk factors for parental burnout [47]. In one study, mothers reported managing their own fatigue to be the most difficult care-giving task when caring for a child with a chronic illness [44].

A number of unmodifiable risk factors also emerged and could be used to identify ‘at risk’ parents. These included lower education level, being a single parent, lower socio-economic status, race (being Black), and being a young parent [6, 10, 48]. Other risk factors included having severe life stressors, low self esteem, lower family cohesion, marital conflict, and being less optimistic [17, 31, 34, 45].

### Summary of Factors Associated with Poorer Parent Wellbeing

- Role strain and low satisfaction with basic needs leads to more depressive symptoms via higher use of emotion-focused coping.
- Caregiver reports of burden of illness on family predict more caregiver psychiatric symptoms.
- Using different communication styles/coping strategies between partners is associated with poorer parental wellbeing.
- Passive avoidance (e.g. smoking, alcohol consumption), cognitive avoidance (e.g. not thinking about the disease, occupying thoughts elsewhere) and a lack of social support are also associated with poorer parent wellbeing.
- A parent neglecting their own health (e.g. refusing medication, not getting regular health checks) is also associated with poorer wellbeing.
- Unmodifiable risk factors include lower socio-economic position, being a single parent, lower education level and low self-esteem.

### 4.6 PARENT STRATEGIES TO ENHANCE CHILD WELLBEING

#### Results from Reviews

There were three reviews, all from the UK, that looked at parent strategies to enhance child wellbeing. These consisted of a Cochrane Review, a narrative review and a systematic literature review. The number of studies in the reviews ranged from 13-20. Two reviews focused on parents of children with cystic fibrosis and type-1 diabetes, while the other included parents of children with various chronic diseases (asthma, chronic pain, chronic fatigue syndrome, diabetes, juvenile idiopathic arthritis and paediatric cancer). Two reviews included children and adolescents (0-21 years), and one focused on adolescents (13-16 years) only.

A Cochrane Review of psychological interventions (mainly behavioural and educational) for children and adults with cystic fibrosis and their immediate family identified few studies (6/13 randomised controlled trials) which measured outcomes related to mental health (i.e. most outcomes were related to issues of adherence, change in physical status or other specific treatment concerns) [13]. Parents applying behavioural strategies such as massage therapy and music as adjuncts to their children’s physiotherapy showed a consistently beneficial effect, as evidenced by reductions in children’s anxiety and increased enjoyment. Other interventions...
involved educational tools and implied that providing information to children about their illness and promoting self-management improved wellbeing.

In a systematic review of qualitative studies of adolescents with type-1 diabetes, several themes were identified which highlighted a number of potentially helpful parenting strategies [53]. Parental trust in adolescent’s ability to manage their diabetes reduced anxiety. Parents found it helpful to change their own expectations of perfect diabetes management in order to reduce family conflict. On the other hand, unnecessary parental input and intrusiveness may cause parent-child conflict and affect adolescent’s self-esteem and confidence.

Other coping mechanisms related to structure and routine, such as parents creating new family routines and lifestyle changes to cope with the demands of the diabetes regimen, as well as maintaining structured mealtimes. However, some adolescents perceived changes to family life as a negative consequence due to conflicts and inconvenience.

Barlow and Ellard [54] provided an overview of the evidence base for the effectiveness of psychoeducational interventions for children and adolescents with chronic disease (and their parents and siblings). Psychoeducational interventions can include the simple provision of information but may also entail group activities focused on the learning specific disease management techniques. Interventions were mainly cognitive-behavioural in their approach, and drew on concepts such as self-efficacy and empowerment through access to information, ability to make choices, self-esteem and assertiveness. There was evidence for effectiveness of psychoeducational interventions on variables such as self-efficacy, self-management, family functioning, psychosocial wellbeing, isolation, social competence and hope.

<table>
<thead>
<tr>
<th>Summary of Evidence from Reviews for parent strategies to enhance child wellbeing</th>
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<tbody>
<tr>
<td>• Parents incorporating relaxation/distraction strategies into daily therapy routines with their children reduce anxiety.</td>
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<tr>
<td>• Parents need to achieve a balance between holding back input and providing background support for their adolescents with type-1 diabetes.</td>
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<tr>
<td>• It may be helpful to maintain structure and routine in the day to facilitate diabetes management and maintain adolescent mental health.</td>
</tr>
<tr>
<td>• Providing information to children about their illness and promoting self-management and independence appears to improve child wellbeing and family functioning.</td>
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**Results from Interventional Studies**

There were two intervention studies, one from the US and one from Europe. Interventions were targeted at children in mid-late childhood with cystic fibrosis and type-1 diabetes and their parents. The sample size of Goldbeck and Babka [20] was small (n = 16) making it difficult to detect effects, and the design was quasi-experimental (i.e. no control group). However, Grey et al. [55] was a two-group experimental design and thus a stronger study, with 82 school-aged children randomized to an intervention or control group.

Grey et al. [55] investigated the effect of a group-based coping skills training for school-aged children with type-1 diabetes and their parents, compared to a general group education, on children’s quality of life, depressive symptoms, coping, diabetes self-efficacy and family functioning. The intervention aimed to increase children’s sense of competence and mastery by improving communication, social problem solving, recognition of associations between thoughts, feelings and behaviours, self-talk, stress management and conflict resolution around diabetes-
specific stressors. There were no significant group differences. Children in both groups showed improved mood, quality of life, coping and self-efficacy. It is possible that non-specific factors such as peer support, present in both interventions, may have improved psychosocial adjustment in children with type-1 diabetes.

A family-centred, cystic fibrosis-specific and age-appropriate psychoeducational program was developed to promote families’ (n = 16) coping with cystic fibrosis-related problems, but demonstrated only few effects [20]. Parents reported that their children were actively seeking more social support but were less optimistic, more withdrawn and felt different from peers after the intervention. The apparent negative impacts of the program may have been due to the fact that for most of the children, it was the first time they received comprehensive information about their disease.

<table>
<thead>
<tr>
<th>Summary of Evidence from Intervention Studies for parent strategies to enhance child wellbeing</th>
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<tbody>
<tr>
<td>• Intervention studies assessing parent/child strategies to enhance child wellbeing are scarce.</td>
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<tr>
<td>• Providing the child/adolescent with opportunities to interact/meet peers who also have a chronic illness can improve the child’s social support, sense of belonging and wellbeing.</td>
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<tr>
<td>• One small study suggests that caution must be exercised when delivering comprehensive information to young children (mean age 7 years) about their disease and its treatment, as it may be confronting and detrimental to their psychological health.</td>
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</table>

Results from Longitudinal Studies

Two longitudinal studies from the US examined parents and their children with cancer to determine parental factors that predicted child mental health. One of the studies measured distress in 65 mothers of children (mean age of 8.3 years) and the relationship with parent- and nurse-reported child distress across 24 weeks [56]. High maternal distress, but not declining or low maternal distress, was associated with more severe mother-reported emotional distress in the child. However, the same relationships were not found between maternal distress and nurse-reported child distress, suggesting that parent’s own mental health may affect perceptions of their children’s wellbeing. A second smaller study (n = 23) involving a younger paediatric cancer population (mean age 5.9 years) with a longer follow-up (10-29 months) measured parenting capacity factors and their relation to later child adjustment [57]. Higher parental overprotection, perceived child vulnerability and parenting stress were significantly related to greater child emotional distress and behavioural difficulties at follow-up.

<table>
<thead>
<tr>
<th>Summary of Evidence from Longitudinal Studies for parent strategies to enhance child wellbeing</th>
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<tr>
<td>• Mothers with high levels of emotional distress may be less able to assist their children to cope with their cancer diagnosis and treatment.</td>
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<tr>
<td>• Parenting stress and an overprotective parenting style lead to long-term child emotional and behavioural difficulties.</td>
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**Results from Cross-sectional Studies**

Seven cross-sectional studies, the majority originating in the US and the others from the UK (n = 1) and Europe (n = 2), examined associations between parent or family factors and the mental wellbeing of children with chronic illness [58-64]. The majority of studies (n = 5) involved participants in mid- to late childhood and two included both children and adolescents [63, 64]. Correlates of psychological wellbeing were examined for children or adolescents diagnosed with asthma (n = 2), a range of chronic illnesses (n = 2), diabetes (n = 1), eczema (n = 1) and chronic pain (n = 1).

Studies by Reichenberg et al. [61] (n = 59) and Dennis et al. [59] (n = 74) investigated the role of the family environment in promoting adjustment in children with asthma and eczema, respectively. Children with eczema who had fewer adjustment problems were from family environments which were supportive, not controlling or conflicted, and where the impact of the condition on the family was smaller [59]. Similarly, children with asthma from cohesive family environments had higher self-esteem and fewer behavioural and emotional problems than those children from less cohesive families [61]. A larger study by Wysocki and Gavin [64] investigated father’s involvement (n = 190) in the management of their child’s chronic disease, and found that greater paternal involvement was associated with better quality of life among adolescents but not children. Across these three studies, all effects were small (where reported), and child psychological adjustment was assessed by parent-report only, with the exception of a measure of child self-esteem in one study.

Three of the cross-sectional studies examined whether parental responses to their children’s chronic illness, such as their communication or parenting styles, were associated with child psychological adjustment. A small study of young children with type-1 diabetes and their mothers (n = 40) assessed maternal communication styles via objective observation and self-report measures [58]. More frequent commands which constrained the child’s participation in an activity were associated with greater externalising problems. On the other hand, more frequent use of statements which assigned responsibility to the child (i.e. to take action or make a choice), correlated with fewer internalising and behaviour problems. In Immelt et al.’s [60] study of 190 mother-child dyads, chronically ill children who perceived a high level of support and acceptance from their mother reported higher self-esteem and fewer mood difficulties. Finally, for children with chronic pain, a parenting style characterised by protectiveness partially mediated the relationship between pain-specific parent distress and poorer child adjustment [63]. This suggested that parents who were distressed were more likely to adopt protective behavioural responses towards their children, which may worsen child adjustment.

Other studies have also examined whether parent’s own distress and coping styles are associated with their children’s psychological adjustment. One study supported associations between the coping ability of parents (n = 89) and the psychological wellbeing of their asthmatic children [62]. When mothers with asthmatic children relied on avoidance coping (i.e. distancing themselves from the stressor), their children had higher anxiety (small effect), while those who employed cognitive coping (i.e. reframing the situation to cope with the stressor, such as looking for the positive in what was happening) had children with better asthma-related quality of life. Furthermore, mothers who were worried and perceived a large impact of the disease on the family reported poorer psychological adjustment in their sick children [60], while parents who perceived that they had control of the management of their child’s illness reported their children as better adjusted [61].
However, as all the above studies are cross sectional, it is impossible to determine the nature and direction of the relationships between family factors and children’s psychological adjustment i.e. whether these factors cause or are affected by children’s adjustment.

### Summary of Evidence from Cross Sectional Studies for parent strategies to enhance child wellbeing

- The psychological wellbeing of chronically ill children is enhanced within cohesive and supportive family environments.
- Children who are encouraged by their parents to make decisions and participate in activities, despite their chronic illness, may experience better psychological health.
- Over-involved/protective parenting can lead to child externalising problems and poorer child adjustment.
- Parents should try to minimise their own distress as this may improve child wellbeing directly and/or via less over-involved and protective parenting.
- Providing parents with practical and active ways to control their child’s chronic illness (e.g. helping children avoid certain foods or allergens), is likely to reduce distress in the parent and child.

### Results from Qualitative Studies

A qualitative study from the US explored coping strategies employed by adolescents with cancer [65]. Adolescents who observe their parents experiencing intense emotions such as fear, anger and sadness in response to the cancer diagnosis may be less likely to discuss concerns with their parents, for fear it may cause further distress. They may also try to shield their parents from uncomfortable feelings by avoiding discussing issues such as their fear of death. Adolescents with cancer who sense changes in family routines, organisation and relationships among family members may experience guilt and some may attempt to compensate by adopting a strong and fearless demeanour. Parents who shield their chronically ill child by avoiding discussing issues of fear and uncertainty may unintentionally reinforce the children’s fears about their prognosis.

### Summary of Evidence from Qualitative Studies for parent strategies to enhance child wellbeing

- By regulating their own distress about their child’s chronic illness, parents can increase the likelihood of their child communicating openly about their own emotions.
- Adolescents should be actively encouraged to express painful emotions and to discuss difficult topics such as the fear of death.
- Adhering to daily routines, maintaining relationships and reducing family conflict during the time of diagnosis and treatment will enhance adaptive coping in adolescents with cancer.

### 4.7 CHILD STRATEGIES TO ENHANCE THEIR OWN WELLBEING.

### Results from Reviews

In a systematic review of qualitative studies, several themes were identified which highlighted potentially helpful strategies for adolescents with type-1 diabetes [53]. Attending diabetes camps and school trips appears to provide safe environments to enhance self-management of type-1 diabetes which can increase self-esteem. For adolescents, it was important for them to disclose their diabetes to their friends, as it helped them to feel safe knowing their friends could cope in an
emergency and therefore to forget about their diabetes when with their peers. Adolescents appreciated reassurance from parents about complications related to their illness and blood glucose fluctuations. They also benefited from structure and routines for their diabetes management.

**Summary of Evidence from Reviews**
for child strategies to enhance their own wellbeing

- For adolescents with type-1 diabetes, attending diabetes-specific camps improves self-esteem.
- Informing friends about their chronic illness and adhering to routines may assist adolescents to cope with a chronic illness.

**Results from Interventional studies**

In a pilot study from The Netherlands of a group and home-based exercise program for children with asthma (n = 7), children engaged in physical activity and were provided with information about asthma and coping strategies for dealing with asthma during exercise [66]. Coping with asthma and expectations of physical competence in sports improved significantly post-program.

A small US study of children (n = 11) and adolescents (n = 5) with cancer and their parents measured change in anxiety following a single tailored yoga session [23]. Results suggested that a yoga class, consisting of seated meditation and standing/balance poses with relaxation music, decreased anxiety in adolescents but not children. All participants reported positive feelings after the intervention.

**Summary of Evidence from Interventional Studies**
for child strategies to enhance their own wellbeing

- Participation in physical activity, despite chronic illness, can enhance children’s psychosocial functioning.
- Relaxation strategies, such as yoga, can improve subjective wellbeing in adolescents with cancer.

**Results from Longitudinal Studies**

We found no articles addressing this area.

**Results from Cross-sectional Studies**

One study from the UK investigated relationships between the coping styles adopted by adolescents with chronic pain, and their emotional distress [67]. Adolescents who tended to catastrophise (e.g. think the pain will never stop) or externalise (e.g. express their anger behaviourally) were more anxious and depressed. On the other hand, seeking social support and employing behavioural distraction (e.g. doing something fun) were associated with fewer symptoms of psychological distress.

**Summary of Evidence from Cross-sectional Studies**
for child strategies to enhance their own wellbeing

- Social support is important for the wellbeing of adolescents with chronic pain.
- Distraction techniques, such as engaging in a pleasant activity, reduce distress in adolescents with chronic pain.
**Results from Qualitative studies**

A qualitative study from Canada investigated support, education needs and preferred interventions of 6-12 year old children with asthma and/or severe allergies [68]. Children identified their mothers as their primary source of support and education about the disease. Most children indicated they wanted some form of peer support and reported they would benefit from additional education about asthma. They preferred the option of peers (i.e. older children with asthma) or a facilitator/mentor directing a support group and talking about asthma, rather than professionals or teachers. Another qualitative study from the US reported that adolescents with cancer often perceive discussions about their treatment and prognosis as forbidden [65]. Consequently, they can ruminate about these fearful topics alone which can increase their sense of isolation. Open and honest discussions about their concerns can lead to improved coping for all family members. Adolescents with cancer who feel ‘betrayed by their bodies’ may attempt to gain a sense of control by becoming noncompliant with treatment or engaging in reckless behaviour.

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**Summary of Evidence from Qualitative Studies**

*for child strategies to enhance their own wellbeing*

- Children with asthma want peer support, and may be more receptive to education about asthma from older children with the same condition, rather than from professionals or teachers.
- Children may benefit from having someone they can relate to as a role model who is also coping with the same chronic illness.
- Adolescents with cancer find it liberating to discuss fears of death, dying and recurrence, particularly with peers in a similar situation.
- Developing new interests and participating in group therapy with other adolescent cancer patients may reduce the risk of self-destructive behaviour.

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**4.8 PARENT STRATEGIES TO ENHANCE SIBLING WELLBEING**

**Results from Reviews**

Three reviews, one each from the UK, Brazil and the US, examined the role of parenting factors and sibling intervention programs in influencing the wellbeing of siblings of children with chronic illness. Each review contained a similar number of studies (n = 15-17). Two reviews focused on siblings of children with cancer and two included siblings of children with a range of chronic illnesses and developmental disorders (e.g. autism). Most of the reviews examined family-level determinants of sibling adjustment (e.g. social support and family characteristics) while one paper specifically reviewed support for participation in camps [71]. None of the reviews were systematic and none evaluated research quality.

da Silva et al. [14] synthesised the literature in relation to the benefits of social support for family members of children with cancer; 6/15 papers were specific to outcomes for healthy siblings. Examples of useful strategies included opportunities for siblings to talk (e.g. in support groups), to participate in the care for the sick sibling and to be responsible for small duties at home to help them feel important. Other ideas concerned maintaining open communication within the family, providing information, and maintaining contact with the sick sibling (e.g. by visiting hospital).

O’Brien et al. [69] included studies of healthy siblings across childhood and adolescence. Results indicated a role for social support, consistent family routines and effective communication in protecting against emotional and behavioural problems in healthy siblings. Siblings of families with...
parental stress, more children and lower socioeconomic status were at a disadvantage. There was strong evidence for the benefits of sibling intervention programs (e.g. camps), particularly those providing both individual and combined family support. Aims of the camps, family-based interventions and sibling support groups included increasing knowledge and understanding of their sibling’s illness or disability, facilitating children’s communication, as well as enhancing coping and problem-solving. These strategies were related to better adjustment in siblings such as increases in perceived control, improvements in self-esteem and reduced anxiety.

In Hancock’s [71] review, all of the studies suggested that the camp experience has a positive impact on the emotional wellbeing of siblings of paediatric cancer patients, both in the short- and long-term. Goals of the camps include providing education about cancer and its treatment, peer support, addressing emotional concerns, validating feelings and improving self-esteem. Other useful strategies identified by siblings included keeping their lives as normal as possible, relief from guilt and reassurance about the health of the sick child and their own health.

Bellin and Kovacs [70] reviewed the literature for risk and protective mechanisms, at the level of the family and environment, influencing the psychosocial outcomes of well siblings of children with chronic health conditions. Themes at the family-level were related to mutual support and collaboration and balancing the needs of the sick child with those of the rest of the family. It was also suggested that the well sibling be involved in the process, by being encouraged to express their emotions, being provided with accurate information and developing supportive relationships with members of the health care team. At the environmental level, it was recommended that siblings be connected to support groups where the unique stressors they face can be addressed and their experiences validated.

### Summary of Evidence from Reviews for parent strategies to enhance sibling wellbeing

- There is a dearth of studies (particularly randomised controlled trials) focusing on interventions for siblings.
- Emotional and informational support can help children to learn mechanisms to deal with having a sibling who is chronically ill.
- Allowing opportunities for the healthy sibling to play an active role within the family and in the care of the sick child may increase their self-esteem and sense of control.
- Keeping routines, maintaining open communication within the family and providing the sibling with information about the chronic illness and its treatment all improve sibling wellbeing.
- Parents are generally the gate-keepers to sibling’s access to peer support. Therefore it is important for parents to be familiar with the structure, benefits and availability of peer support programs, including sibling camps which have numerous benefits (e.g. improved self-esteem, reduced guilt and reassurance about their own health).

### Results from Interventional studies

There were three studies, one each from Australia, the US and Canada, investigating the mental health outcomes of group intervention programs for siblings of chronically ill children. All of the study designs were quasi-experimental without comparison groups. Two studies with small sample sizes (n = 26, n = 17) evaluated the benefits of peer support groups for siblings of children with cancer [72, 73] and another with a larger sample size (n = 54) examined an integrated group intervention for siblings and parents of children with chronic illness or disability [74]. The majority of well siblings were in mid-childhood or early adolescence, although one study also included siblings in mid- and late adolescence [72].
There were common aims across both of the therapeutic peer support programs: to increase sibling’s knowledge about cancer and its treatment, improve social competence and address emotions. Both interventions were based on cognitive-behaviour therapy principles and involved opportunities to develop peer support networks and to participate in developmentally appropriate activities. When comparing sibling’s mental health pre- and post-program for both interventions, anxiety and cancer-related fears were reduced. Other improvements specific to each study included improvements in social competence and depression and behaviour problems [73].

An integrated sibling-parent group intervention also involved education about chronic illness/disability, addressed sibling emotions and enabled children to participate in social-recreational activities [74]. When comparing sibling’s mental health pre- and post-program, improvements were noted in behaviour, knowledge of the child’s disorder and sense of connectedness.

<table>
<thead>
<tr>
<th>Summary of Evidence from Interventional Studies for parent strategies to enhance sibling wellbeing</th>
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<tbody>
<tr>
<td>• Increasing children’s knowledge of their sibling’s chronic illness may be beneficial when done in a supportive, group environment.</td>
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<tr>
<td>• It may be helpful to provide siblings with the opportunity to meet others who are experiencing similar circumstances (e.g. at therapeutically designed camps) to reduce isolation and enhance social competence.</td>
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<tr>
<td>• It is difficult to determine which elements of the interventions account for improvements in sibling mental health.</td>
</tr>
</tbody>
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**Results from Longitudinal Studies**

A single longitudinal study from The Netherlands (n = 85) of 7-19 year olds examined whether coping strategies, family adaptability/cohesion or parent distress predicted psychological adaptation of siblings of childhood cancer patients [75]. Family adaptability, as defined by the level to which a family adapts its power structure, role definitions, and rules according to internal and external demands, emerged as an important construct. Results highlighted the importance of a balanced family structure that incorporated both stability and change. Children who maintained a positive, optimistic view regarding their sibling’s illness felt less anxious, insecure and lonely at follow-up. On the other hand, strategies that relied on the expertise of the medical specialist or a search for meaning and understanding were associated with sibling distress.

<table>
<thead>
<tr>
<th>Summary of Evidence from Longitudinal Studies for parent strategies to enhance sibling wellbeing</th>
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<tr>
<td>• Siblings need to be offered realistic information about the chronic illness without undermining all sense of hope.</td>
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<td>• Parents can encourage their children to use cognitive strategies that focus on the positive aspects of the situation.</td>
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**Results from Cross-sectional Studies**

There were seven cross-sectional studies, originating in the US (n = 4), UK (n = 2) and Europe (n = 1), which examined associations between parent or family factors and the adjustment of children or adolescents with a chronically ill sibling. Several studies involved siblings with ages ranging from middle childhood through to adolescence (n = 6), while one study focused on children only [3].
Correlates of psychological wellbeing were examined for siblings of children diagnosed with cancer (n = 5), cystic fibrosis (n = 1), a range of chronic illnesses (n = 1) and type-1 diabetes (n = 1).

Most studies examined the role of social support as perceived by the siblings [2, 3, 76] or parents [77-79] and the adjustment of healthy siblings. In studies by Barrera et al. [2] and Alderfer and Hodges [76], siblings who perceived more social support appeared to have fewer symptoms of depression, anxiety, and behaviour/academic problems, as reported by the parent and child, than siblings who perceived lower social support [2]. Friends were considered the most important and greatest source of social support to siblings of children with cancer, while support from parents and teachers were of equal importance [76].

School-aged siblings identified interventions that were directed at meeting their needs for emotional and instrumental support (as opposed to informational or appraisal support) as most beneficial [3]. This suggests that siblings need to be given opportunities to express their feelings and concerns about issues surrounding their sibling’s cancer experience, and that they also benefit from practical assistance such as transportation to after-school activities, help with homework and other tasks that help maintain a sense of normality and daily routine.

Parental satisfaction with social support [77-79] and the availability of resources [78] were also consistent protective factors for the wellbeing of healthy siblings. On the other hand, relationships between higher parent distress and emotional problems among siblings were reported in some studies [77, 79] but not others [78]. Siblings who were more poorly adjusted perceived the illness to have a negative impact on interpersonal relationships, such as loss of attention from parents and feelings of neglect [78]. Furthermore, siblings with emotional problems were more likely to have parents who were not aware of their attitudes and perceptions about the chronic illness experience [79].

Together, these studies highlight the importance of parents linking-in with personal and community supports to help alleviate the burden of care [79]. This may assist them to protect their own mental health, as well as enable them to understand and attend to the emotional and practical needs of the healthy sibling.

Houtzager et al. [75] examined associations between reliance on four cognitive coping strategies (predictive, vicarious, interpretive and illusory control) and quality of life in siblings of children with cancer. Siblings with optimism, or who maintained a positive outlook (predictive control) reported higher cognitive and emotional quality of life. On the other hand, children who desired to understand the meaning of the illness and asked questions about their sibling’s illness (interpretive control) experienced fewer positive emotions. This suggests that when seeking information, siblings may become more aware of the negative and distressing realities of the illness. However, in another study, parents reported less negative behaviours in siblings when there had been discussions about the child with cystic fibrosis with the medical team [77].
Results from Qualitative studies

Three studies used interview methods to collect qualitative data from parents [80], siblings [81] and both parents and siblings [82] of children with a chronic illness. They examined families of children with diabetes, cancer and a range of chronic illnesses. Sibling ages ranged from childhood through to early and mid adolescence.

Parents report mixed opinions about the provision of diabetes education to the well sibling. Parents believe it is beneficial for healthy siblings to be included in education sessions but also noted that the children can become bored and not understand the content if it is not developmentally appropriate [82]. Parents noted that siblings can misinterpret the information provided, for example, by assuming responsibility for causing the illness [80]. Siblings themselves reported that a lack of knowledge about the illness was a source of stress [81].

Some siblings enjoy participating in diabetes management (e.g. fetching equipment and comforting their brother or sister during procedures) and do not perceive the increased responsibility as a burden [82]. Furthermore, being involved in the care of the chronically ill child may strengthen the sibling relationship [82]. Parents noted that the added responsibility of having a sibling with diabetes creates more maturity in the healthy child [82]. On the other hand, when siblings felt overburdened with responsibility, this was stressful [81].

Siblings reported fears they could develop a chronic illness themselves and felt anxious about the chronically ill child dying or being in pain [81, 82]. Parents mentioned that siblings were anxious due to the unpredictable nature of the chronic illness and its prognosis, treatment and effects [80]. Siblings who reported anxiety about causing their sibling’s illness reported that they used ‘compensatory strategies’ such as praying or visiting the sibling frequently, to make up for being healthy themselves [81]. The negative impact of having a chronically ill sibling may be exacerbated by extreme thinking styles that focus on the worst-case scenario (i.e. catastrophic thinking). Engaging in magical/omnipotent thinking (e.g. believing that if you think something, it will happen) can also create a burden of responsibility in the sibling to keep the sick child alive [81].
Studies suggest that a lack of attention on the well sibling may result in feelings of isolation [80-82]. Parents admitted that becoming distracted while involved in procedures with their diabetic child leads to siblings feeling left out [82]. They also reported that siblings perceive a lack of fairness when parents appear to be overindulging and over-protecting the chronically ill child [82]. Siblings themselves identified multiple sources of stress related to their parents’ behaviour, which included differential treatment or preoccupation with their sick brother or sister and parental distress in relation to the chronic illness [81]. Being reprimanded by parents for being selfish if they expressed feelings, or being told to ignore negative thoughts were unhelpful strategies, while affection, time with parents and having questions answered were considered by siblings to be helpful [81].

Parents commented on the value of sibling camps. Their perceived benefits related to the focus being on the well sibling instead of the sick child, providing a space for self-expression and clarification of information and opportunities for siblings to meet others in similar family situations [80].

The need for predictability and control through maintaining a daily routine was a consistent theme raised by parents and siblings. Siblings expressed anger over the interruption of the daily routine by medical procedures, changes in food choices and reduced time with parents [81, 82]. Parents in another study also reported that siblings reacted with anxiety to changes in family structure, routine and particularly, separation from their parents and other members of the immediate family [80].

<table>
<thead>
<tr>
<th>Summary of Evidence from Qualitative Studies for parent strategies to enhance sibling wellbeing</th>
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<tbody>
<tr>
<td>• Enabling the well sibling to participate in the practical and emotional care of the child with chronic illness benefits the sibling relationship and their emotional maturity. At the same time, parents need to be careful not to overburden the child with responsibility.</td>
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<tr>
<td>• Well siblings can be supported and reassured through the provision of education that is age-appropriate and presented in a manner that is engaging.</td>
</tr>
<tr>
<td>• Maintaining daily routines and ensuring the well child is not neglected during medical-related procedures or crises reduces sibling anger, anxiety and perceived isolation.</td>
</tr>
<tr>
<td>• Siblings should be given the space and time to express their fears, worries and health-beliefs. This may provide opportunities to correct misconceptions about the chronic illness (e.g. diabetes is contagious) and omnipotent beliefs (e.g. angry thoughts can cause illness or death) which can exacerbate distress.</td>
</tr>
<tr>
<td>• Parents can help children to regain perspective if they are ruminating about worst-case scenarios.</td>
</tr>
<tr>
<td>• Sibling camps have a positive impact on wellbeing through increased social support and the provision of chronic illness information.</td>
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### 4.9 RESULTS FROM WEB-BASED RESOURCES AND EXPERTS IN THE FIELD

We consulted with a number of experts at the RCH, Melbourne and searched a number of websites cited in articles identified during the review. First, we present a summary of strategies parents can use to enhance a) their own wellbeing and b) sibling wellbeing, identified from web-based resources and experts in the field. Next, we present a summary of parent strategies recommended for use with their ill children when they are feeling stressed, sad, scared, worried,
overwhelmed or anxious. In most cases, this information was provided to parents via referral to the websites or from printed handouts with instructions for using each strategy. Finally, a list of other relevant web-based resources is provided.

**Parent strategies to enhance their own wellbeing**

Several parent strategies to enhance their own wellbeing were recommended in ‘The Information Book’ (an electronic book given to families of children with a diagnosis of cancer in Victoria, see below) and from clinicians from the Children’s Cancer Centre, RCH. These included:

- Take care of relationships (e.g. open communication between parents).
- Maintain good social support networks.
- Maintain ‘self-care’ (e.g. parents remember to look after themselves, have a break from caregiving duties etc).

A US website provides ‘tips’ for carers of children with a chronic illness to enhance parent mental wellbeing. The following recommendations are summarised below and can be accessed from the following weblink: [http://kidshealth.org/parent/system/ill/caregivers.html?tracking=P_RelatedArticle](http://kidshealth.org/parent/system/ill/caregivers.html?tracking=P_RelatedArticle).

- Take breaks (spending time engaged in a relaxing or enjoyable activity).
- Ensure good nutrition and regular exercise to help relax, encourage good sleep patterns and reduce stress.
- Stay organized with the child’s medical routine (e.g. appointments, medications).
- Seek help when needed and find a support group.
- Acknowledge feelings and recognize signs of ‘caregiver burnout’ (i.e. physical and emotional exhaustion).

**Parent strategies to enhance sibling wellbeing**

Parent strategies to enhance sibling wellbeing identified in ‘The Information Book’ included:

- Organise a trusted relative or friend who comes specifically to see the other children regularly.
- Remind family and friends to ask about and visit the other children.
- Ensure that the kinder/school is aware of their brother/sister’s illness.
- Request a buddy system to support the well child. For example, a class teacher might check on the child each day. The teachers may make sure that the child knows who to talk to at school if he/she is feeling upset.
- Ensure that the well children have contact with a trusted adult friend outside the immediate family who they can talk to about their worries.
- Ensure that the siblings are included in the treatment plan where possible and appropriate.
- Ensure that the siblings are able to access age-appropriate child-friendly information about your child’s cancer.
- Have a regular special time with each sibling where they can discuss anything that might be on their mind.
- Where possible ensure that the sibling/s have time for normal activities.

**Parent strategies to enhance child wellbeing**

Several strategies parents can adopt to enhance their child’s mental wellbeing were identified from web-based resources and consultation with experts. A summary of these strategies is provided below. These are derived from an electronic resource available to parents who have a child diagnosed with cancer in Victoria (entitled “The Information Book: Life after Diagnosis”) and

- Guided imagery (e.g. parents instructing children to visualize themselves as a floppy noodle, relax specific parts of the body such as their toes, or visualize being in a safe comfortable place).
- Social stories (e.g. allied health staff write a story where the child is the main character and the illness journey is pictured and described, parents then read the social story to their child to minimise distress through being mentally prepared).
- Problem solving and emotion coaching techniques (e.g. parents are instructed to listen to their child’s feelings, reflect empathy and communicate understanding(validate child’s concerns and worries).
- Relaxation techniques (e.g. parents are given information and strategies to assist their child with calm breathing, muscle relaxation).
- Open communication between parent and child (allow the child to express their feelings).
- Maintain a consistent environment and routine for the child with access to familiar things (e.g. toys) to minimise separation anxiety.
- Parents are encouraged to try to get their child to do a normal activity.
- Maintain family rules and expectations about the child’s behaviour.
- Provision of strategies for the child to release tension (e.g. punching bag, access to a trampoline).
- Social support (e.g. parents encourage the child to maintain contact with his / her friends to help the child feel better emotionally but also to help with his / her return to school and other normal activities).

Other helpful communication and parenting strategies were identified from the Australian government’s Raising Children Network website [http://www.raisingchildren.net.au](http://www.raisingchildren.net.au) and include:

- Take a few minutes to gather yourself together before you talk to your child about the issue.
- Let your child see you’re upset, but reassure him you’ll be OK.
- Take charge.
- Try not to let the situation grow bigger than it really is.
- Talk to your child.
- It’s OK to say ‘I don’t know’.
- Tell your child what he needs to know
- Let your child know if it’s an adult problem.
- Reassure your child, and remember that actions speak louder than words.
- Spending extra time putting your child to bed can be useful.
- Encourage your child with hope and optimism.

**Other useful web-based resources**

[http://www.med.umich.edu/yourchild/topics/chronic.htm#familydo](http://www.med.umich.edu/yourchild/topics/chronic.htm#familydo)
[http://www.cfw.tufts.edu/?/category/resources-recreation/5/topic/chronic-illness-support/124/](http://www.cfw.tufts.edu/?/category/resources-recreation/5/topic/chronic-illness-support/124/)
5. REFERENCES


