

# Counselling and psychological therapy for children with long-term medical conditions (LTCs): a narrative review of the literature

Nicky Paris & Alison Brettle  
on behalf of BACP

April 2015

BACP has used reasonable endeavours to ensure that the material contained in this bulletin was correct at time of creation.

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source and no commercial usage or sale.

Reproduction for other purposes than those indicated above requires written permission of the copyright holder, application for which should be addressed to the Chief Executive at BACP.

© BACP 2015

## Contents:

<b>Executive summary</b>	<b>2</b>
Prevalence	2
Quality of the evidence	2
General and multiple conditions	2
Asthma	3
Diabetes	4
Myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS)	5
Conclusions	5
<b>Aim</b>	<b>7</b>
<b>Methods</b>	<b>7</b>
<b>General and multiple conditions</b>	<b>10</b>
Background	10
Overview of the evidence	10
(Table 1)	11
Outcome measures	13
Interventions and effectiveness	13
<b>Asthma</b>	<b>15</b>
Background	15
Overview of the evidence	16
(Table 2)	17
Outcome measures	18
Interventions and effectiveness	18
<b>Diabetes</b>	<b>20</b>
Background	20
Overview of the evidence	21
(Table 3)	22
Outcome measures	25
Interventions and effectiveness	25
<b>Myalgic encephalomyelitis/Chronic Fatigue Syndrome</b>	<b>27</b>
Background	27
Overview of the evidence	28
(Table 4)	29
Outcome measures	31
Interventions and effectiveness	31
<b>Conclusions</b>	<b>32</b>
General overview	33
Psychological interventions for children with long-term medical conditions	34
Effectiveness of psychological therapies for children with long-term medical conditions	34
Implications for practice, research and policy	34
<b>References</b>	<b>37</b>

## Executive summary

Seeking to answer some general questions about children facing long-term medical conditions, the most common forms of psychological therapy available to them, and the evidence for the effectiveness of those therapies, a search of key databases was conducted. Filtering and selection narrowed the field to 71 papers, and selection via quality and relevance of the available evidence led to this report focusing on papers looking at multiple long-term conditions, asthma, diabetes and myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS). These conditions were found to have the most extensive and highest quality evidence bases.

This narrative report summarises the current literature on psychological therapy for children with long-term medical conditions.

## Prevalence

It is difficult to estimate the prevalence of chronic long-term medical conditions in children, but it is believed to have doubled in the last 20 years. Asthma is identified in the literature as the most common long-term medical condition in children across all age groups affecting one in seven children in the UK. One in 500 children in North America has diabetes. There is a wide variation in estimates of the prevalence of ME/CFS – from 0.0006% to 2% of children and adolescents.

The literature exploring multiple conditions does not discriminate between age group or gender. Indeed some studies reviewed did not report details of their participants so it is difficult to draw conclusions about variations in prevalence across age groups and gender. However, in the literature on diabetes, adolescence was described as a time of particular difficulty in managing the condition, as children transition to self-management. The literature on ME/CFS focuses on older children (10 years plus) and adolescents. Whether this suggests that this is a condition that increases in prevalence in later childhood/adolescence, or whether this is when children are diagnosed, is unknown.

## Quality of the evidence

Despite a number of Cochrane Reviews and systematic reviews, the evidence for the effectiveness of psychological therapies for children with long-term medical conditions is inconclusive. This is because the diversity of outcome measures makes it difficult to conduct meta-analyses or pool results. Also, there is a very wide range of interventions that are sometimes not well described, making comparison difficult.

There is a body of evidence for psychological interventions for ME/CFS that is conclusive enough for authors to endorse recommending Cognitive Behavioural Therapy (CBT) for children and young people with ME/CFS.

## General and multiple conditions

Children with long-term chronic medical conditions, and their families, are managing highly complex treatment regimens often involving drug treatments, dietary requirements and physical therapy. Not adhering to treatment can lead to compromised quality of life. This issue has led to the development of psychological interventions specifically targeted at 'treatment adherence'. The kinds of interventions available are wide ranging and the literature categorises them as educational interventions, behavioural interventions

(including CBT-based interventions), multi-component interventions, and psychosocial interventions. Some technology-based interventions were also identified within the literature. The effectiveness of these interventions is measured in a variety of ways, but usually by using some method for monitoring adherence to treatment.

Educational interventions alone were found to be less effective at promoting adherence to treatment than when combined with behavioural elements or in multi-component interventions, where evidence of effectiveness was found. Behavioural interventions were found to be effective at promoting adherence to treatment. Psychosocial interventions showed some promising results.

It is recognised that parenting a child with a chronic long-term medical condition can be difficult and that poor family functioning can impact the child's condition. Parents can positively influence the child's adjustment to having a long-term condition. There is a body of evidence concerning interventions for parents measured through six outcome domains: parent behaviour, parent mental health, child behaviour/disability, child mental health, child symptoms and family functioning. CBT was found to be effective for influencing a child's symptoms and problem solving therapy (PST) was found to be effective for parental behaviour and mental health. No significant effect was found for family therapy or multisystemic therapy (MST).

More generally, there was evidence for the effectiveness of psychological interventions, regardless of modality or condition, as an adjunct to treatment as usual, and there was a small qualitative exploration of professionals working with families that found family therapy and individual therapy eased stress but that peer support was also important.

Despite evidence of the effectiveness of behavioural, multi-faceted interventions (CBT and PST) there was little evidence of the effects being sustained over a longer-term period.

### **Asthma**

There are two main issues explored in the literature concerning asthma: poorly controlled asthma and difficult asthma. Patients with poorly controlled asthma take up a disproportionate amount of healthcare resource – it is estimated that 10% of asthma sufferers in the UK take up 50% of resources – making it a significant policy issue. Difficult asthma is defined as asthma not controlled by standard treatment and it is believed that 10% of patients have difficult asthma.

The literature describes a wide range of interventions for children with asthma, which target treatment adherence, symptom management and quality of life. A primary outcome measure described throughout the literature is healthcare use and includes reporting on number of hospitalisations, visits to A&E or to a GP. Secondary outcomes described are related to asthma symptoms – measures of lung function, airway inflammation and severity of symptoms, for example using the number of asthma attacks and frequency of medication use (as medication is often used on an as-needed basis in the treatment of asthma). Other secondary outcome measures include absences from school, psychological questionnaires and change in behaviour scales. This range of measures makes it difficult to pool results.

Similarly, there are a range of interventions explored in the literature, which have been broadly categorised as psycho-education (including multi-faceted interventions such as psycho-education combined with family therapy), relaxation-based interventions (including relaxation with guided imagery), CBT and behavioural interventions, and art therapy. Psycho-educational interventions were found to be effective in reducing healthcare admissions. Among children with difficult asthma, psycho-education was found to be effective in reducing hospital admissions. Psycho-educational interventions were effective for significant improvements in overall health-related quality of life scores and, when combined with family therapy, were found to improve treatment management and airway inflammation. Relaxation-based interventions were associated with a reduction in hospital admissions, improvements in anxiety, some impact on symptom severity (although this was mixed) and depression. Behavioural and cognitive behavioural therapies were associated with significant improvement in self-management, coping and asthma specific anxiety, while, in a small study, art therapy was associated with reduced worry and improved scores on the Beck Anxiety Inventory and self-concept and general quality of life measures.

### Diabetes

Diabetes is identified within the literature as a particularly complex condition to manage for children and young people. The influence of family relationships and conflict are identified as factors in how successfully the disease is managed. Adolescence is identified as a particularly difficult time in the management of the disease as children transition into self-management with family dynamics identified as having a major influence on this process. A small proportion of patients have poorly controlled diabetes and these patients make disproportionate use of medical resources.

There are a wide variety of interventions identified and evaluated in the literature most of which are specific to addressing the needs of patients with diabetes. Effectiveness is measured by looking at health outcomes and adherence to treatment regimens, but there are some studies that use self-report on family relationships and behaviour change to measure effectiveness. Interventions are often family orientated, and look at influencing the behaviour of the individual with diabetes and their family members. Some interventions consider the wider context around the child such as school.

Family-oriented interventions were found to be clinically effective in improving health outcomes but this was not statistically significant. There is insufficient evidence for the effectiveness of psycho-educational interventions, in part because of the variety of interventions and numerous ways of measuring outcome. A small study of a cognitive behavioural intervention aimed at treatment adherence found some improvements in self-care.

The range of interventions and outcome measures used with children and young people with diabetes makes it difficult for researchers to draw conclusions as to the relative effectiveness of psychological interventions. Researchers have identified specific groups at risk of managing their diabetes poorly as being under-represented in the research, and issues of cost effectiveness and access are touched upon, but not fully explored.

### Myalgic encephalomyelitis/chronic fatigue syndrome

An issue specific to ME/CFS is diagnosis. The two main diagnostic tools cited in the literature are from the Centre for Disease Control and Prevention in the US, and the Oxford Diagnostic Criteria in the UK. However, other criteria for diagnosing ME/CFS were used in individual studies meaning that there could be variation in participants' characteristics (Knight et al, 2013). Current guidelines recommend the use of CBT in the treatment of ME/CFS.

Outcome is measured in a wide range of ways – from severity of fatigue and physical functioning to psychological measures (which include the Beck Depression Inventory, and the Hospital Anxiety and Depression Scale among others). Measuring outcome in terms of school attendance was most often used across the literature.

The majority of interventions described in the literature were variations on CBT and there is reasonably strong evidence for the effectiveness of CBT for children and adolescents with ME/CFS. CBT is associated with improvements in school attendance, self-reported improvements in fatigue severity and physical and psychological functioning. There is more mixed evidence for the long-term effectiveness of CBT-based interventions, with a psycho-education control group being found to be as effective at long-term follow up as family-focused CBT. There is emerging evidence of the effectiveness of an internet-based CBT intervention for adolescents with ME/CFS. There is also some limited evidence of the effectiveness of narrative self-investigation.

### Conclusions

The key issues surrounding children with long-term medical conditions are the management of their treatment and the ability of children and their families to adhere to complex regimes; the management of difficult diseases which can lead to the disproportionate use of healthcare services by a few patients; the complexity of parenting a child with a chronic condition which can influence treatment adherence and the child's wellbeing and general health-related quality of life.

A wide range of psychological interventions have been developed for children with long-term health conditions to impact upon these issues, which range from condition specific psycho-education, through multi-faceted interventions that combine psycho-education with behavioural or cognitive behavioural therapy, to art therapy and relaxation-based interventions. It is worth noting the lack of research and therefore evidence of the effectiveness of counselling and psychotherapy for children with long-term medical conditions.

There are various approaches to measuring the effectiveness of interventions. Primary outcome measures tend to be adherence to treatment, or healthcare use, with secondary measures including measuring symptoms, psychological measures of anxiety, and school attendance/absenteeism. For ME/CFS, the primary measure seemed to be school attendance.

The literature does not demonstrate the particular effectiveness of one intervention over another. Psychological interventions showed evidence of effectiveness, to significant levels, on some outcome measures, but not consistently across all outcome measures. Researchers

note throughout the literature, that the lack of consistency in the description of interventions and the use of such a variety of outcome measures make it difficult to pool results. The literature on ME/CFS yielded enough results for the general conclusion that CBT is associated with an increase in school attendance, justifying, according to researchers, CBT as the recommended psychological intervention for this condition.

Researchers also report inconsistent results at follow-up, suggesting that psychological interventions may need to be integrated into longer-term clinical care which is a key issue for healthcare providers. However, they note a lack of follow-up studies.



# Counselling and psychological therapy for children with long-term medical conditions (LTCs): A narrative review of the literature

## Aim

In providing a narrative overview of the evidence for the impact of counselling and psychological therapies on children with long-term medical conditions, this review seeks to consider the following questions:

*What are the most common forms of long-term conditions for children?*

*What is the prevalence of these LTCs?*

*How do they vary across different age groups?*

*What are the most common forms of psychological therapies for these populations?*

*What evidence is there relating to the effectiveness and acceptability of these interventions?*

*What are the implications for policy, practice and research?*

## Methods

A search of three databases was conducted; selected to incorporate both psychological and medical perspectives. These included PubMed – medical literature; PsychINFO – psychological literature and the Cochrane Library – ‘high’ quality evidence of a range of medical and social interventions. The search focused on terms that would retrieve any counselling or psychotherapy modality and the most common long-term conditions affecting children. The search terms used included: long-term conditions; chronic illness; asthma; diabetes; renal or kidney; multiple sclerosis. No long-term condition was deliberately excluded, but only those with the above keywords were deliberately included, thus any article using the terms long-term or chronic would retrieve additional conditions. The search was limited to children and/or adolescents (or similar terms), research literature published within the last 10 years and incorporated all counselling modalities. The number of results returned were as follows:

- PubMed: 1387
- PsychINFO: 285
- Cochrane: 1934

These were filtered, and on the basis of title, assessed for relevance to the topic area. The following exclusion criteria were applied:

- Adults or not child specific (unless a review which covered both).
- Genetic counselling.
- Preventative/advice giving interventions for problems such as obesity, health and lifestyle, smoking.
- Education only type interventions.
- Mental health (e.g. anxiety or depression).

The resulting relevant papers (on the basis of abstracts) were then themed by condition as follows: general or multiple conditions; asthma, ME/CFS, cystic fibrosis; eczema; Human

Immunodeficiency Virus (HIV); Irritable Bowel Syndrome (IBS); mental health; nocturnal enuresis; pain; renal; sickle cell and sleep disorder.

Using a pragmatic system based on study design and the hierarchy of evidence (Guyatt et al, 1995), rather than full critical appraisal, papers were classified as follows:

- Two star papers: high quality evidence based on more than one study, for example systematic reviews.
- One star papers: good quality evidence based on more than one study, for example non-systematic reviews or individual randomised controlled trials (RCTs).
- No star papers: other study designs.
- Background papers.

A subsequent search focused on papers reporting evidence for counselling interventions. Counselling interventions were those that met the BACP definition of counselling (BACP, 2010).

Searches yielded a total of 71 papers, as follows:

- Two star: 20 papers.
- One star: 40 papers.
- Non RCT (no stars): three papers.
- Background (B): four papers.
- Non RCT evidence for 'counselling' interventions: four papers.

We then filtered the subject areas by volume of papers and levels of evidence, considering two and one star papers only to refine our selection. This gave us the following sections based on considering only the conditions with the best quality evidence:

- general or multiple conditions: seven papers (including two papers reporting non-trial evidence for counselling );
- asthma: six papers;
- diabetes: 15 papers; and
- ME/CFS: eight papers.

This report is based upon reviewing the two and one star papers either in full paper or abstract. As this report is written for counselling practitioners, we also included the non-trial evidence for counselling interventions. However, only two were available for inclusion within this report (Burton, 2010; Morison, Bromfield & Cameron, 2003). Hafkamp-de Groen, et al (2010) was excluded because the paper reports on a trial protocol and not on evidence. Lanzarote Fernandez & Torredo Val (2009) was not available either in abstract or full paper form. Where an exclusion criterion (e.g. an excluded condition) is included within a paper reporting a systematic review, it has been excluded from this report. In the case of systematic reviews, the general findings are reported rather than a detailed appraisal of the individual papers included in the review.

This is a systematic report of the current literature attempting to capture the information most relevant for counsellors and psychotherapists without conducting a full critical

appraisal of each study. The author (NP) has extracted the evidence presented in the literature on the basis of availability and interest to practitioners. The terminology used within this report has been taken from the literature and has not been subjected to scrutiny. As we have based this report on papers published, multiple papers may be reporting data derived from a single study.

## General and multiple conditions

### Background

In the US, Canada, Northern Europe and Australia, chronic conditions are reported to be common in children, and are thought to have doubled in the last 20 years (Eccleston, Palermo, Fisher & Law, 2012). The high prevalence of chronic illness in children means that large numbers of children and their families are managing highly complex treatment regimens that include drug treatments, diet and physical therapy (Kahana, Drotar & Frazier, 2008) and face challenges that can affect their quality of life (Thompson, Delaney, Flores & Szigethy, 2011). Estimates suggest that not adhering to treatment is common (Dean, Walters & Hall, 2010) and runs at an average of 50% or more for asthma, juvenile rheumatoid arthritis and diabetes, effectively leaving the condition untreated (Kahana et al, 2008). Treatment non-adherence could lead to the development of other symptoms, complications, increased use of healthcare and a decrease in quality of life for the child (Dean et al, 2010). It is not possible to simply translate research from adult populations with chronic illness to child populations, because there are specific influences upon a child's ability to adhere to treatment, for example, familial influence (Dean et al, 2010). These issues have led to the development of psychological interventions specifically targeting adherence to treatment in children (Dean et al, 2010).

It is now recognised that parents suffer significant emotional distress of their own, in response to a child having a chronic condition. While poor family functioning can impact the outcomes of the child, equally, parental responses can have a positive effect on how the child adjusts to chronic illness (Eccleston et al, 2012). Morison et al (2003) suggest that chronic illness is a traumatic event for the whole family. This recognition has led to the development of psychological interventions for parents to help both themselves and their children (Eccleston et al, 2012).

A wide range of conditions were represented in the general literature which included tuberculosis treatment and prophylaxis (Dean et al, 2010), asthma (Dean et al, 2010; Eccleston et al, 2012; Kahana et al, 2008), HIV (Dean et al, 2010), epilepsy (Dean et al, 2010); juvenile rheumatoid arthritis (Dean et al 2010; Eccleston et al, 2012), sickle cell prophylaxis (Dean et al, 2010), renal transplant (Dean et al, 2010), diabetes (Dean et al 2010; Kahana et al, 2008), cystic fibrosis (Eccleston et al 2012; Kahana et al, 2008). Eccleston et al (2012) looked at a very wide definition of long-term health conditions and included painful conditions, traumatic brain injury and cancer in their definition.

### Overview of the evidence

Five papers were identified as either two star or one star papers. Two more papers were identified and included in this report as they examine counselling interventions that may be of interest to practitioners (see Table 1).

**Table 1: General and multiple conditions**

Paper	Topic area	Main conclusions	Design of study	Quality of study	Reviewed for this report	Location of study/studies	No. of participants
Beale (2006)	Efficacy of psychological interventions for children with chronic illness (diabetes, cancer, cystic fibrosis and sickle cell disease).	Psychological interventions are generally effective and are associated with large effect sizes across a wide range of outcomes when used alongside usual treatment. Only tentative conclusions can be drawn until there is more research with stronger designs.	Literature review	One star	Abstract	Not stated in abstract	19 studies.
Burton (2010)	Supporting adolescents with a sibling with a life threatening illness.	Family support alongside individual support eases stress, and peer support considered important.	Qualitative	No stars	Abstract	UK	Eight participants.
Dean, Walters & Hall (2010)	Interventions that enhance medication adherence in children with long-term health conditions (TB prophylaxis; TB treatment, asthma, diabetes, epilepsy, HIV, juvenile rheumatoid arthritis, sickle cell prophylaxis, renal transplant).	Psycho-education alone is not enough to increase medication adherence but combined with a behavioural component interventions become more effective.	Systematic review	Two stars	Full paper	Not stated.	17 studies. Participants range in age from nine months to 19 years.
Eccleston, Palermo, Fisher & Law (2012)	Psychological interventions for parents of children and adolescents with chronic illness (various pain disorders and painful conditions, rheumatological conditions (e.g. arthritis and fibromyalgia), sickle cell disease, cancer, diabetes mellitus, asthma, traumatic brain injury, inflammatory bowel diseases (IBDs), skin diseases (e.g. eczema), gynaecological disorders).	Good evidence for the effectiveness of including parents in CBT for children with chronic illness and for problem solving therapies on skills and parental mental health, immediately after treatment.	Systematic review	Two stars	Full paper	Not stated.	35 RCTs involving 2723 participants.
Kahana, Drotar, & Frazier (2008)	Psychological interventions to promote adherence to treatment in children (46% involved asthma; 23%	Behavioural and multi-component interventions effective in promoting adherence to treatment.	Meta-analysis	Two stars	Full paper	Not explicitly stated although cultural and ethnic origins of	70 studies; participants' mean age ranged from

	diabetes; 14% cystic fibrosis, 3% juvenile rheumatoid arthritis and obesity 1% each for hemodialysis, hemophilia, HIV, inflammatory bowel disease (IBD), phenylketonuria (PKU), seizure disorders, sickle cell disease, and TB).						some participants described as African American so can assume US.	two to 15 years. 82% Caucasian, remaining African American or other.
Morison, Bromfield & Cameron (2003)	Exploring a therapeutic model for families supporting children with a chronic disease	A flexible, family-centred model is described which draws on the dynamics of hope, empowerment, reconnection, coping/resilience and reframing.	Descriptive	No stars	Abstract	Abstract	Authors based in Australia	Not stated.
Thompson, Delaney, Flores, & Szigethy (2011)	CBT for children with physical illness (diabetes, IBD, cancer, sickle cell disease).	CBT findings explored and future research recommendations addressed.	Review	One star	Abstract	Abstract	Not stated in abstract.	Not stated in abstract.

## Outcome Measures

A wide variety of outcome measures are used in the literature. In one review, 62 outcome variables were identified (Beale, 2006). Many studies explore adherence to treatment regimen and a range of measures were used to do this (Kahana et al, 2008). Taking medication was measured using electronic monitoring (MEMS), which uses a device that measures the time and frequency of bottle opening; by self or parental reports of tablets taken, diaries or behaviour; serum/urine tests of drug concentration and pharmacy dispensing records (Dean et al, 2010).

To examine the impact of psychological interventions for parents, Eccleston et al (2012) identified six outcome domains: parent behaviour, parent mental health, child behaviour/disability, child mental health, child symptoms and family functioning.

It was not possible to identify outcome measures from the abstracts of Thompson et al (2011) and Morison et al (2003). Burton (2010) explored the issues faced by participants through semi-structured interviews, and used a grounded theory analysis.

## Interventions and effectiveness

There were a wide range of interventions explored within the literature, delivered in many ways. Fifty-two per cent of the interventions in one review (Kahana et al, 2008) were delivered in groups, 40% individually, and the remainder both. Most interventions were delivered to children and their parents, with 24% delivered to children only, and 8% to parents only. A small percentage, 5%, were designed for children, parents, wider family and the community (such as school). Some interventions were computerised or delivered through game-based technology (Kahana et al, 2008). Interventions were delivered by a wide range of professionals (Kahana et al 2008).

Beale (2006) found general evidence, with large mean effect sizes, of the efficacy of adjuvant psychological interventions for children with chronic illness and concluded that effect sizes were not significantly moderated by illness type or the type of intervention used.

Two large systematic reviews specifically focused on psychological interventions targeting treatment adherence (Dean et al, 2010; Kahana et al, 2008). They identified different kinds of interventions as follows:

### Educational interventions

Educational interventions were described as verbal and written information about the condition, rationale for treatment and the benefits of adhering to the treatment regime (Dean et al, 2010; Kahana et al, 2008).

Dean et al (2010) examined seven studies, comparing an educational intervention with treatment as usual. Although there was some evidence of improvement to treatment adherence, when compared to a control group, it was not statistically significant. Twenty-six per cent of studies in Kahana et al (2008) looked at educational interventions. Despite most

interventions including an element of education there were few studies in which an improvement in adherence was shown.

### Behavioural interventions

Behavioural interventions included monitoring and goal setting, reinforcing taking medication with rewards, contingency contracting, problem-solving, linking taking medication with established routines (Dean et al 2010; Kahana et al 2008) and parent training (Kahana et al, 2008).

There was evidence that behavioural interventions had an impact on adherence to treatment (Dean et al, 2010). Behaviour management was associated with a significantly greater number of tablets being taken (Dean et al, 2010). However, there was no clear relationship between the intensity or duration of the intervention and effectiveness (Dean et al, 2010). CBT for children with comorbid conditions was explored in one review (Thompson, et al, 2011).

### Multi-component interventions

Multi-component interventions most often included behavioural and educational elements, or social support, social skills training or family therapy elements combined with either a behavioural or educational element (Kahana et al, 2008).

A behavioural management and educational combination was associated with a significantly greater percentage of asthma medication doses being taken by adolescents with depression (Dean et al, 2010). In participants with depression, education and CBT were associated with poorer medication adherence compared with treatment as usual (Dean et al, 2010). Education and stress management in adolescents with diabetes was associated with poorer adherence than the control. In adolescents with asthma, education and group therapy led to better adherence at 24 months but not at 12 months after treatment (Dean et al, 2010).

### Psychosocial interventions

Psychosocial interventions looked at broad issues that included family functioning and/or crisis interventions (Kahana et al, 2008). These interventions were associated with small to medium effect sizes, making it difficult to draw firm conclusions (Kahana et al, 2008).

### Use of technology

Kahana et al (2008) found evidence of technology or interactive computer-based games which focused on a specific condition and treatment being used to promote adherence, with no person-to-person interaction. The effect size for these interventions was not significantly different than zero.

### Psychological interventions for parents/family members

One review looked specifically at interventions for parents (Eccleston et al, 2012). CBT for parents was found to have a significant effect on child symptoms but no significant effect was found at follow-up. The overall effect of problem solving therapy on parent behaviour



and parent mental health was significant (Eccleston et al, 2012). There was no evidence of significant effect of family therapy or multi-systemic therapy (Eccleston et al, 2012).

The overall effect of psychological therapies for parents on child symptoms was significant (Eccleston et al, 2012) but there were no significant effects at follow-up. For diabetes and asthma there were no significant results on efficacy of psychological therapy for parents (Eccleston et al, 2012).

Burton (2010) undertook semi-structured interviews with counsellors and other professionals working with clients who have a sibling with a life-threatening illness. A grounded theory analysis found that family therapy, as well as individual therapy, eases stress for families and peer support was also considered important.

## Asthma

### Background

Asthma is a chronic inflammatory disease of the airways which sometimes causes them to narrow, often in response to external triggers (Smith et al, 2005), which could be chemical, physical or emotional (Yorke, Fleming, & Shuldham, 2005). It causes breathlessness, cough, wheeze and chest tightness (Smith et al, 2005; Yorke, et al 2005). Asthma is the most common chronic condition that affects children of all age groups in Britain with estimates suggesting that one in seven children have asthma (Smith, et al, 2005). It is also the most common chronic childhood disease in the US and accounts for 14.6 million lost school days (Kapoor, Bray & Kehle, 2010). The symptoms of asthma may limit physical activity and have an impact on the social and emotional aspects of a child and their family's life (Kapoor, 2007; Yorke et al, 2005). Children with asthma are at risk of compromised health-related quality of life (HRQOL) (Clarke & Calam, 2012).

Education about asthma, self-management training, relaxation and other stress management techniques, and support for managing the impact of having a chronic condition are the interventions found to be available for children from the literature (Smith et al, 2005). These are considered as 'psycho-educational' interventions (Smith et al, 2005). Psycho-educational interventions have been found to be effective in improving the symptoms of asthma (Ng, et al 2008).

Psychosocial issues impact on both the condition itself and the ability of the individual or their family to manage the condition, which in turn affects the condition (Smith et al, 2005). Emotional stress can precipitate or exacerbate both acute and chronic asthma (Kapoor et al, 2010; Yorke et al, 2005). About one third of all children diagnosed with asthma also have an anxiety disorder and those patients report poorer quality of life and more healthcare visits (Kapoor et al, 2010).

The literature identifies two specific issues in relation to asthma: poorly controlled asthma and 'difficult' asthma. Patients with severe or poorly controlled asthma take up a disproportionate amount of healthcare resources. It is thought that 10% of asthma patients in the UK account for more than 50% of the costs, and that three quarters of those patients present with asthma that is poorly controlled (Smith et al, 2005). Difficult asthma is defined as 'disease that remains poorly controlled despite medical treatment that would normally be effective' (Smith et al, 2005, p2). It is believed that 10% of patients have difficult asthma

(Smith et al, 2005). In recent UK studies, it was reported that more than 70% of patients dying from asthma had significant psychological or social factors that may have contributed to their deaths (Smith et al, 2005).

### **Overview of the evidence**

Six papers were identified that looked at a range of psychological interventions for children with asthma. The papers identified are detailed in Table 2.

**Table 2: Asthma**

Paper	Topic area	Main conclusions	Design of study	Quality of study	Reviewed for this report	Location of study/studies	No. of participants
Beebe, Gelfand & Bender (2010)	The effectiveness of art therapy for children with asthma.	Benefits include decreased anxiety and increased quality of life.	Randomised controlled trial: art therapy intervention vs wait-list control group.	One star	Abstract	Not stated in abstract.	22 participants
Clarke & Calam (2012)	The effectiveness of psychosocial interventions designed to improve health-related quality of life.	Four studies reported that psychosocial interventions were effective for significant improvements in HRQOL scores. Most interventions focused on delivery of asthma education to children but more multi-component interventions that combine education with behavioural change strategies are called for, and also interventions that address the needs of the wider family.	Systematic review	Two stars	Abstract	Not stated in abstract.	18 studies
Kapoor, Bray & Kehle (2010)	Relaxation and guided imagery in schools for children with asthma and anxiety.	Increase in lung function and lowering of anxiety scores found.	Multiple baseline study design	One star	Abstract	Authors based in US. Not explicitly stated in abstract.	Three participants
Ng, Li, Vivian, Lou, Tso, Wan & Chan (2008)	The effectiveness of an asthma psycho-educational programme that incorporates family therapy.	Decrease in airway inflammation and increase in adjustment and efficacy of asthma management scores. Results support the inclusion of family therapy in a psycho-educational intervention.	Randomised wait-list controlled crossover clinical trial.	One star	Abstract	Not stated in abstract.	46 participants
Smith, Mugford, Holland, Candy, Noble, Harrison, Koutantji, Upton & Harvey (2005).	Psycho-education and its impact upon health outcomes and costs in adults and children with difficult asthma.	Overall psycho-education interventions improved hospital admissions and symptoms in children with difficult asthma but there was a limited effect on other outcome measures.	Systematic review	Two star	Full paper	Over half the individual studies took place in the US, five in the UK and eight in other European countries, two in New Zealand and one each in Canada and Brazil.	35 papers (children). Individual studies report variable sample sizes ranging from 16 to 1033 participants. Mean sample size given as 118.
Yorke, Fleming, & Shuidham (2005)	Psychological interventions for children with asthma.	Meta-analysis was possible on only two studies examining the effects of relaxation on peak flow rate, which found relaxation intervention to be effective. Unable to draw firm conclusions so the review demonstrates an inadequate evidence base and highlights the need for high quality randomised controlled trials.	Cochrane Systematic review	Two star	Standard paper	Not stated	12 studies: 588 children

## Outcome measures

The effectiveness of interventions for children with asthma is measured in range of ways. Yorke et al (2005) report on primary outcomes as health service use which was measured across the literature using hospital admissions, accident and emergency (A&E) attendances, GP use and unscheduled healthcare attendances (Smith et al, 2005; Yorke et al, 2005). Secondary outcomes were lung function (Kapoor et al, 2010; Smith et al, 2005; Yorke et al, 2005), airway inflammation (Ng et al, 2008; Yorke et al 2005) and severity of asthma symptoms (Smith et al, 2005). Severity of asthma symptoms (Smith et al, 2005) were measured using a range of indicators including the number of asthma attacks, asthma severity scales, monitoring medication use and combined data relating to the duration of an asthma attack, the medication taken, A&E visits and hospital admissions, to calculate an overall effect of therapy (Yorke et al, 2005).

Other measures included absence from school (Smith et al, 2005; Yorke et al, 2005), psychological questionnaires related to self-efficacy (Smith et al, 2005; Yorke et al 2005), adjustment to asthma (Ng et al, 2008), health status (Smith et al, 2005), medication use (Smith et al, 2005), quality of life (Smith et al, 2005; Clarke & Calam, 2012; Beebe, Gelf & Bender, 2010), coping, and anxiety and depression (Beebe et al, 2010; Yorke et al, 2005). Change in behaviour scales and asthma knowledge questionnaires were also used (Yorke et al, 2005) and in one study, the Formal Elements Art Therapy Scale was applied to the Person Picking an Apple from a Tree assessment (Beebe et al, 2010).

Outcomes in parents were measured using perceived efficacy in asthma management, Hospital Anxiety and Depression Scale anxiety subscale, Body Mind Spirit Wellbeing Inventory emotion subscale and Short form 12 health-related quality of life scale (Ng et al, 2008).

## Interventions and effectiveness

Generally the literature reports on a wide range of interventions, with little description available of the specific intervention used.

### Psycho-education

Psycho-educational interventions aim to improve health outcomes by facilitating changes in patients' behaviour, thoughts and emotions related to asthma and its management (Smith et al, 2005). Interventions included in this section contain an element of psycho-education (Clarke & Calam, 2012; Smith et al 2005) and include purely psycho-educational interventions and those incorporating some element of self-management. Multi-faceted interventions are described as incorporating an element of focused medication management (Smith et al, 2005). Clarke and Calam (2012) describe interventions as psychosocial but they are reported as incorporating asthma education, with and without problem solving techniques. Ng et al (2008) report on a trial incorporating family therapy into a psycho-educational intervention.

Psycho-educational interventions were found to be unlikely to harm clients, but were found to be less effective than routine treatment or non-psycho-educational interventions (Smith et al, 2005). There was evidence that psycho-educational interventions reduce hospital admissions when data was pooled across nine studies (Smith et al, 2005). The most

significant results for psycho-educational interventions improving hospital admissions were found in children with difficult asthma (Smith et al, 2005). Generally, there was little evidence supporting the effectiveness of psycho-education programmes on A&E attendances (Smith et al, 2005).

Psycho-education based interventions may reduce asthma symptoms in children (Smith et al, 2005) and some positive effects were found for self-care behaviour (Smith et al, 2005). Interventions that incorporated self-management (i.e. self-monitoring and use of action plans) appeared to have the greatest effects, followed by multi-faceted interventions (i.e. interventions that also include helping participants self-manage their concurrent medical treatment) and educational interventions (Smith et al, 2005).

Psychosocial interventions designed to improve health-related quality of life were delivered in numerous settings and formats and focused on a range of psychosocial, healthcare, school-related and clinical outcomes. Most interventions were psycho-educational, looking to improve asthma knowledge and disease management in children. In the Clarke & Calam (2012) systematic review, asthma education (two studies), asthma education plus problem solving, (one study) and art therapy (one study) were reported as effective for significant improvements in overall health-related quality of life scores.

Psycho-education incorporating family therapy was associated with a significant decrease in airway inflammation, an increase in patients' adjustment to asthma and parents' perceived efficacy in asthma management. This trend is reported as continuing steadily after the intervention (Ng et al, 2008).

#### Relaxation-based interventions

A range of relaxation-based interventions are reported on in the literature (Kapoor et al, 2010; Yorke et al, 2005). In the Yorke et al (2005) review, bio-feedback assisted relaxation is reported as having a significant impact on hospital admissions but no significant impact on asthma severity. A bio-feedback assisted relaxation treatment group reported significant improvements in anxiety in two studies using different measures (Yorke et al, 2005). Bio-feedback and self-hypnosis were associated with fewer emergency room visits for acute asthma attacks but showed no statistical significance (Yorke et al, 2005). Relaxation was reported in one study as having an impact on lung function, and significant improvements on asthma severity (based on participant reports); but no significant change was reported on the behaviour change checklist. Depression was described as improving significantly in patients who participated in this intervention (Yorke et al, 2005). Progressive relaxation demonstrated a significant improvement in asthma symptoms in one study. Fewer changes in medication use were observed but this was not significant (Yorke et al, 2005). When compared to a control treatment, bio-feedback was associated with significant improvement in as-needed medication use. In one study participants in the treatment group showed greater improvement than those in the control group in asthma attitude (measured using the Asthma Attitude Survey for Children), although results were not significant. There was little difference between treatment group and control when self-concept was measured (Yorke et al, 2005). Guided imagery assisted relaxation was associated with a statistically significant increase in asthma knowledge; however, when measuring school absences, results were mixed (Yorke et al, 2005). In a school-based intervention (based on a theory

that mind and body play a role in determining health outcomes) a 20-minute intervention, given an average of three times per week over a four-week period, improved lung function and lowered anxiety scores in the three participants (Kapoor et al, 2010).

### Cognitive behavioural and behavioural therapy

Behavioural therapy is associated with a significant decrease in as-needed medication and significant reduction in school absenteeism (Yorke et al, 2005). CBT demonstrated significant improvement in asthma knowledge; significant improvement in self-management scores; significant improvement in coping scores; and a significant reduction in asthma specific anxiety in extremely anxious children; but no significant changes in trait anxiety levels (Yorke et al, 2005).

### Art therapy

There is some evidence within the literature for the use of art therapy for children with asthma (Beebe et al, 2010; Clarke & Calam, 2012). A 60-minute art therapy session, delivered once a week for seven weeks, in which therapy tasks were designed to encourage expression, discussion and problem-solving in response to the emotional burden of chronic illness, was associated with improved problem solving and affect drawing scores, improved worry, communication and total quality of life scores, improved Beck anxiety and self-concept scores. While some positive changes were maintained at six-month follow-up, the intervention did not demonstrate impact upon frequency of asthma attacks. The benefits of art therapy were found to be on decreasing anxiety and increasing quality of life (Beebe et al, 2010; Clarke & Calam 2012).

## Diabetes

### Background

One in 500 children in North America have diabetes (Couch, Jetha, Dryden, Hooton, Liang, Durec, Sumamo, Spooner, Milne, O’Gorman & Klassen, 2008; Harris, Freeman & Beers, 2009; Naar-King, Ellis, Idalski, Frey & Cunningham, 2007). Type 1 diabetes (destruction of the cells that produce insulin) and Type 2 diabetes (decrease insulin sensitivity and production) share a similar, complex management (Harris et al, 2009). The majority of the literature evidences the experiences of individuals with Type 1 diabetes (Couch et al, 2008; Ellis, Frey, Naar-King, Templin, Cunningham & Cakan, 2005; Ellis, Naar-King, Frey, Templin, Rowland & Cakan, 2005; Ellis, Naar-King, Templin, Frey & Cunningham, 2007; Ellis, Templin, Naar-King, Frey, Cunningham, Podolski & Cakan, 2007; Ellis, Yopp, Templin, Naar-King, Frey, Cunningham, Idalski & Niec, 2007; Lehmkuhl, Storch, Cammarata, Meyer, Rahman, Silverstein, Malasanos & Geffken, 2010; McBroom & Enriquez, 2009; Murphy, Rayman & Skinner, 2006; Nansel, Iannotti & Lui, 2012; Naar-King et al, 2007; Savage, Farrell, McManus & Grey, 2010; Silverman, Hains, Davies & Parton, 2003) with some exploration of the experiences of participants with Type 2 diabetes (Harris et al, 2009; Ellis, Naar-King, Chenc, Moltz, Cunningham & Idalski-Carcone, 2012).

Diabetes is a particularly challenging condition because its management requires daily medical tasks (Lehmkuhl et al, 2010). There are high risk implications for not adhering to treatment (Ellis, Frey et al, 2005) which can result in serious medical conditions including

diabetic ketoacidosis (DKA)<sup>1</sup>, the most common acute cause of hospitalisation and death in children and young people with diabetes (Lehmkuhl et al, 2010).

Moving into adolescence is associated with deterioration in management of treatment for young people with Type 1 diabetes as young people become responsible for managing their condition (Ellis, Frey et al, 2005; Nansel et al, 2012; Lehmkuhl et al, 2010; Harris et al, 2009, Naar-King et al, 2007). A small proportion of young people are particularly poor at controlling metabolism and this group takes up a disproportionate share of the cost of health care (Ellis, Frey et al, 2005; Naar-King et al, 2007). The experiences of young people with poorly managed diabetes are specifically explored within the literature (Ellis et al, 2012; Ellis, Naar-King et al 2005; Ellis, Naar-King et al, 2007; Ellis, Templin et al, 2007; Ellis, Yopp et al, 2007; Harris et al, 2009; Lehmkuhl et al 2010).

Family support is known to impact upon young people's adherence to treatment (Ellis, Frey et al, 2005) and other influencing factors are low socioeconomic status (Lehmkuhl et al, 2010), being from single parent families (Ellis, Frey et al, 2005), and how responsibility for care is distributed within a family (Naar-King et al, 2007). Ability to access medical support is also thought to influence ability to adhere to treatment (Ellis, Frey et al, 2005; Lehmkuhl et al, 2010).

### Overview of the evidence

Our search found 15 papers graded one or two stars, looking at psychological interventions with children and adolescents with diabetes. The papers identified are detailed in Table 3 below.

---

<sup>1</sup> Diabetic ketoacidosis (DKA) is defined by Diabetes UK as follows: 'Consistently high blood glucose levels can lead to a condition called diabetic ketoacidosis (DKA). This happens when a severe lack of insulin means the body cannot use glucose for energy, and the body starts to break down other body tissue as an alternative energy source. Ketones are the by-product of this process. Ketones are poisonous chemicals which build up and, if left unchecked, will cause the body to become acidic – hence the name "acidosis"' (Diabetes UK, 2014).

Table 3: Diabetes

Paper	Topic area	Main conclusions	Design of study	Quality of study	Reviewed for this report	Location of study/studies	No. of participants
Couch, Jetha, Dryden, Hooton, Liang, Durec, Sumamo, Spooner, Milne, O’Gorman & Klassen (2008)	Diabetes education for children.	General diabetes education and CBT were found to be effective but the diversity of interventions meant that no one intervention was found to be more effective than any other. Conclusion that there is insufficient evidence to identify a particular intervention that is more effective than standard care to improve diabetes control, quality of life, or reduce short-term complications.	Systematic review	Two star	Full paper	Not stated.	80 studies with between 11-332 participants.
Ellis, Frey, Naar-King, Templin, Cunningham, & Cakan (2005).	Multisystemic therapy (MST) for adolescents with poorly controlled diabetes.	Intensive, home-based psychotherapy is effective in reducing diabetes-related stress in adolescents with poorly controlled disease.	RCT	One star	Full paper	Midwestern City, US.	127
Ellis, Naar-King, Chenc, Moltz, Cunningham & Idalski-Carcone (2012).	Multisystemic therapy compared to telephone support for adolescents with poorly controlled diabetes.	Multisystemic therapy improved health outcomes when compared with telephone support. Home-based approaches may be a viable means of support for young people with diabetes.	RCT	One star	Abstract	Not stated in abstract.	146
Ellis, Naar-King, Frey, Templin, Rowland & Cakan (2005).	Multisystemic therapy and adolescents with poorly controlled diabetes – effects on medical resource use.	MST has the potential to decrease inpatient admissions among adolescents with poorly controlled diabetes.	From RCT	One star	Abstract	Not stated in abstract.	Not stated in abstract.
Ellis, Naar-King, Templin, Grey & Cunningham (2007).	Multisystemic therapy and the role of treatment fidelity in an RCT.	Conducting complex behavioural interventions with a high degree of fidelity can improve treatment outcomes.	From RCT	One star	Abstract	Not stated in abstract.	40
Ellis, Templin, Naar-King, Frey, Cunningham, Podolski & Cakan (2007).	Multisystemic therapy for adolescents with diabetes: looking at the stability of treatment effects.	Intensive, home-based psychotherapy created stable reductions in serious lapses in treatment adherence. One outcome (blood glucose level) was moderated by family composition in that only two-parent families in the multisystemic intervention maintained improvements at follow-up.	From RCT	One star	Abstract	Not explicitly stated in abstract although cultural ethnic origins of some participants described as African American so can assume US.	127 participants. Mean age: 13.2 years. 51% female. 63% African American.



Ellis, Yopp, Templin, Naar-King, Frey, Cunningham, Idalski & Niec (2007).	Family mediators and moderators of treatment outcomes for adolescents with diabetes.	Multisystemic therapy improved family relationships for young people with diabetes in two-parent but not in single-parent families. Multisystemic therapy may improve diabetes related outcomes in single parent families.	From RCT	One star	Abstract	Not stated in abstract.	127 participants.
Harris, Freeman & Beers (2009).	Family therapy for adolescents with poorly controlled diabetes.	Family therapy was associated with a change in family conflict, which has been shown to be associated with reduced treatment non-adherence for adolescents with diabetes.	RCT	One star	Full paper	Midwestern and southeastern USA.	18 adolescents and their parents plus comparisons with 40 participants from a previous study.
Lehmkuhl, Storch, Cammarata, Meyre, Rahman, Silverstein, Malasanos & Geffken (2010).	Telehealth behaviour therapy for adolescents with diabetes.	Telehealth behaviour therapy results in improved glycaemic control and better access to knowledgeable providers. Some participants experienced an increase in unsupported parental behaviours, nevertheless, the authors conclude that telehealth behaviour therapy is a promising method of service delivery.	RCT	One star	Full paper	USA.	32 participants aged between 9 and 17 years; 23 participants were female 81% Caucasian, 12% African American 3.1% Hispanic.
McBroom & Enriquez (2009).	Family-centred interventions to enhance health outcomes of children with diabetes.	Review identified nine publications reporting on randomised controlled trials examining family-centred interventions. Family-centered interventions for children with diabetes appear effective in enhancing health outcomes.	Review	One star	Abstract	Not stated in abstract.	Nine RCTs.
Murphy, Rayman and Skinner (2006).	Psycho-educational interventions for children and young people with diabetes	Review of 27 articles examining the effectiveness of 24 psycho-educational interventions. Concluding that progress in the quality and quantity of research has not resulted in improved effectiveness of interventions and there is still insufficient evidence to recommend adaptation of a particular educational programme.	Review	One star	Abstract	Not stated in abstract.	27 studies. Participant numbers not stated in abstract.
Nansel, Iannotti and Lui (2012).	Clinic integrated behavioural intervention for families of young people with diabetes	This clinic-integrated behavioral intervention was effective in preventing deterioration in glycemic control that is often evident during adolescence in young people with diabetes.	RCT	One star	Full paper	USA	390 families. Patients aged between 9 and 14.9 years.

Naar-King, Ellis, Idalski, Frey & Cunningham (2007).	Multisystemic therapy and family process for type 1 diabetes management in urban young people.	Multisystemic therapy resulted in a significant decrease in parental overestimation of adolescents' responsibility for completion of diabetes care.	RCT	One star	Abstract	Not stated in abstract.	127
Savage, Farrell, McManus & Grey (2010).	Science of intervention development for children with diabetes.	Compared to education interventions, family therapy and most psychosocial interventions were developed with greater scientific rigour and demonstrated promising effects on more health outcomes.	Review	One star	Abstract	Not stated in abstract.	14 RCTs.
Silverman, Hains, Davies & Parton (2003).	Cognitive behavioural adherence intervention for adolescents with diabetes.	Cognitive behavioural intervention was effective in reducing diabetes-related stress in two participants and showed promise in increasing self-care behaviour.	Multiple baseline study design	One star	Abstract	Not stated in abstract	6 participants

### **Outcome measures**

The main desired outcome of psychological interventions for children with diabetes is improvement in the management of the condition. The literature presents a wide variety of ways of measuring outcome, but two main ways emerged: testing for physiological aspects of diabetes and measuring how far participants adhere to their treatment regimens.

The majority of studies measured some kind of metabolic control, for example HbA1c and/or blood glucose testing (Couch et al, 2008; Ellis et al, 2012; Ellis, Frey et al, 2005; Ellis, Naar-King et al 2005; Ellis, Naar-King et al, 2007; Ellis, Templin et al, 2007; Ellis, Yopp et al, 2007; Harris et al, 2009; Lehmkuhl et al, 2010; Nansel et al, 2012; Silverman et al, 2003). The number of hospitalisations and complications reported within the time of the study were also measured (Couch et al, 2008; Ellis, Frey et al, 2005; Ellis, Naar-King et al, 2005; Ellis, Templin et al, 2007; McBroom & Enriquez, 2009).

Adherence to treatment regimen was measured in the form of self-report semi-structured interviews (Ellis, Naar-King et al, 2007; Ellis, Frey et al, 2005; Lehmkuhl et al, 2010; Nansel et al, 2012; Silverman et al, 2003), with one paper looking at both family self-report of an adolescent's adherence to treatment and the adolescent's self-report on adherence (Ellis et al, 2012).

Other outcomes measured include family dynamic examined by looking at conflict and functioning (Harris et al, 2009; Lehmkuhl et al, 2010; McBroom & Enriquez, 2009); diabetes knowledge and quality of life (Couch et al, 2008); and cost effectiveness (Ellis, Naar-King et al, 2005).

Other issues explored in the literature are therapist treatment fidelity in relation to outcomes (Ellis, Frey et al, 2007) and the scientific rigour of the development of interventions (Savage et al, 2010).

### **Interventions and effectiveness**

The majority of interventions examined in the literature combine focus upon the child or young person with diabetes and their family, parent or main carer (Couch et al 2008; Ellis et al, 2012; Ellis, Naar-King et al, 2005; Ellis, Naar-King et al 2007; Ellis, Templin et al, 2007; Ellis, Yopp et al 2007; Ellis, Frey et al, 2005; Harris et al, 2009; Lehmkuhl et al, 2010; McBroom & Enriquez, 2009; Murphy et al, 2006; Nansel et al, 2012). Interventions are multi-faceted and combine elements of education, with problem solving and skills training. Many are described as CBT-based or include some kind of cognitive behavioural element (Couch, 2008; Ellis et al, 2012; Ellis, Naar-King et al 2005; Ellis, Naar-King et al 2007; Ellis, Templin et al, 2007; Ellis, Yopp et al, 2007; Ellis, Frey et al 2005; Harris et al, 2009, Lehmkuhl et al, 2010; McBroom and Enriquez, 2009; Murphy et al, 2006; Nansel et al, 2012).

Savage et al (2010) report on the science of intervention development and its implications for improving health outcomes by reviewing RCTs and identified educational (seven RCTs), psychosocial (five RCTs) and family therapy (two RCTs) interventions. The authors found that family therapy and most psychosocial interventions were developed with greater scientific rigour than educational interventions.

### *Psycho-educational interventions*

The literature describes a huge variation in psycho-educational interventions which include cognitive behavioural therapy, family therapy, skills training and general diabetes education (Couch et al, 2008); 24 different psycho-education programmes were identified for children, young people and their families in one review (Murphy et al, 2006).

There was some evidence of the effectiveness of these multifaceted psycho-educational interventions but there was not enough evidence to say whether any of them were more effective than standard care (Couch et al, 2008). There was not enough evidence to recommend a specific educational programme and no single programme has been proven to be effective in randomised controlled trials for patients with poorly controlled diabetes (Murphy et al, 2006).

### *Family therapy*

The literature describes family-centred interventions (McBroom & Enriquez, 2009) and reports that family therapy and most psychosocial interventions demonstrate more promising effects on health outcome measures than psycho-educational interventions (Savage et al, 2010). Family-centred interventions targeting children appeared to be effective in improving health outcomes, but the interventions were only focused on two-parent families (Ellis, Templin et al, 2007).

### *Multisystemic therapy (MST)*

An intensive form of family therapy, multisystemic therapy (MST), is delivered as either a home-based intervention, or a community based intervention. It draws on CBT, parent training, and behavioural family systems techniques, and includes interventions with the adolescent, main care giver, school and wider community. There is no time limit on the intervention, though in most research, it was tested for approximately six months (Ellis, Frey et al 2005; Ellis et al, 2012; Ellis, Naar-King et al, 2005; Ellis, Naar-King et al, 2007; Ellis, Templin et al, 2007; Ellis, Yopp et al, 2007).

MST was successful in improving metabolic control, but was not statistically significant. However, it is claimed to be clinically meaningful because improving metabolic control has been linked to a reduction in the complication rates of diabetes. There was a significant increase in frequency of adolescent blood glucose testing, compared with the control group but no significant effects were found for insulin or diet adherence (Ellis, Frey et al, 2005). MST was found to have the potential to decrease inpatient admissions and reduce episodes of diabetic ketoacidosis (DKA) (Ellis, Naar-King et al 2005; Ellis, Templin et al, 2007). MST was also reported to improve family relationships for young people with diabetes in two-parent but not in one-parent families (Ellis, Templin et al, 2007). Naar-King et al (2007) found that MST was associated with significant decreases in parental over-estimates of adolescents' responsibility for completion of diabetes care and that this was not moderated by age, family composition or ethnicity.

### *Behavioural family systems therapy*

This is described as a flexible, multi-component diabetes specific intervention targeting

family communication and problem solving (Harris et al, 2009). A home-based version of the therapy was tested in 10 x 1.5 hour sessions over a period of five to eight weeks. All primary adult care-givers of the 18 adolescents recruited to the study participated in the therapy; family composition was one third single parent. This intervention resulted in improvements in parent-reported diabetes specific conflict as well as parent-reported general parent-adolescent conflict, which is understood to be a factor in maintaining regimen adherence (Harris et al, 2009).

#### Telehealth behaviour therapy (TBT)

This is an intensive diabetes specific intervention that has been developed to address barriers-to-access issues in rural communities. TBT sessions were conducted three times a week for 12 weeks by phone, each session lasting on average 15 minutes with the therapist speaking with both the child and parent (Lehmkuhl et al, 2010). This intervention was found to have clinically, but not statistically significant, improvement in glycaemic control. However, some young people reported increased unsupportive parental behaviours as part of the study. The results are described by the authors as promising, although it was not found that TBT was superior to the wait list control (Lehmkuhl et al, 2010).

#### Clinic-integrated behavioural intervention 'WE-CAN manage diabetes'

Grounded in social cognitive theory, self-regulation models and systems theory, this intervention is described as facilitating problem-solving skills, communication skills and responsibility sharing. The intervention combines in-person sessions in clinics with telephone contact and follow-up (Nansel et al, 2012).

Among participants aged 12-14 there was a significant effect on glycaemic control but there was no effect among those aged 9-11. There was no effect upon parent or child reported adherence to treatment. Among adolescents, the effect on glycaemic control was meaningful enough that, if sustained, would result in reducing the long-term risk of complications (Nansel et al, 2012).

#### Cognitive behavioural therapy

In a small scale study, adolescents were trained in cognitive restructuring and problem solving during individual sessions (Silverman et al, 2003). Five (out of six) young people demonstrated improvement on at least one self-care behaviour, and for two participants, the intervention was successful in lowering diabetes related stress. However the participants varied in their response to the intervention (Silverman et al, 2003).

### Myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS)

#### Background

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) is described as profound, medically unexplained fatigue (Knight, Scheinberg & Harvey, 2013) combined with other symptoms such as pain (Knoop, Stulemeijer, Prins, van der Meer & Bleijenbergh, 2007), headaches, sleep disturbance and cognitive difficulties (Chambers, Bagnall, Hempel & Forbes, 2006). Estimates of the prevalence of the condition in children and adolescents vary widely: from .0006% to 2% (Knight et al, 2013). The condition can lead to school absences, which in turn lead to long-term consequences such as reduced physical and psychological wellbeing, impact upon educational achievement, social development and overall quality of life (Knight et al, 2013).

The current guidelines for treatment are based on research into adults, along with clinical consensus (Knight et al, 2013), and recommend CBT-based interventions for psychological therapy. In addition to the wide range of measures, and interventions available, the literature is further complicated by the way in which the condition is diagnosed. There were two main diagnostic criteria cited in the literature: the Centers for Disease Control and Prevention (CDC) or the Oxford criteria, but others were also used in some studies (Knight et al, 2013). The literature reviewed for this report includes research into the effectiveness of all treatments for ME/CFS and not just psychological interventions. Only the evidence on the effectiveness of psychological interventions has been extracted for this report.

### **Overview of the evidence**

Eight papers were identified which are outlined in Table 4.

**Table 4: Chronic fatigue syndrome/ME**

Paper	Topic area	Main conclusions	Design of study	Quality of study	Reviewed for this report	Location of study/studies	No. of participants
Chalder, Deary, Husain & Walwyn (2010)	A trial of family-focused CBT versus psycho-educational intervention.	Adolescents with CFS get back to school more quickly with CBT. However, psycho-education was found to be as effective as family-focused CBT at six and 12 months follow-up, which has implications for health service delivery.	RCT	One star	Abstract	Not stated in abstract.	63 participants, aged from 11 to 18 years; 43 girls and 20 boys.
Chambers, Bagnall, Hempel & Forbes (2006).* **	Interventions for the treatment of chronic fatigue syndrome.	CBT appeared effective at reducing symptoms and improving functioning.	Systematic review	Two stars	Full paper	Not stated.	70 studies include both adults and children.
Knight, Scheinberg & Harvey (2013)*	Interventions for children with chronic fatigue syndrome.	Strongest evidence for CBT interventions but there is limited information on the maintenance of intervention effects. The evidence base for interventions for ME/CFS is still emerging and interpretation of findings is limited by methodological inadequacies and inconsistencies of approach.	Systematic review	Two stars	Full paper	Not detailed.	21 studies. Number of participants ranged from 20 to 159; age ranged from 12 to 16.5 years; majority of participants in all studies were female.
Knoop, Stulemeijer, de Jong, Fiselier & Bleijenberg (2008).	Long-term follow-up of an RCT looking at CBT for children and adolescents with chronic fatigue syndrome.	The cognitive behaviour therapy group was significantly less fatigued, showed better functioning and higher school attendance at follow-up than those in the no-treatment group. The positive effects of CBT were sustained.	Long-term follow-up of an RCT	One star	Abstract	Not stated in abstract.	61
Knoop, Stulemeijer, Prins, van der Meer, Bleijenberg (2007).**	Is CBT for chronic fatigue syndrome also effective for pain?	In patients in recovery, CBT was associated with a reduction in pain. Decrease in fatigue predicted the change in pain severity.	Retrospective analysis of data from previous studies	One star	Abstract	Not stated in abstract.	32 adolescent participants from a previous study.
Lloyd, Chalder & Rimes (2012)	Long-term efficacy of family-focused CBT compared with psycho-education in adolescents.	Both interventions associated with gains that were generally maintained at two-year follow-up. Family-focused CBT was associated with maintained improvements in emotional and behavioural difficulties whereas psycho-education was associated with deterioration in these outcomes between six and 24-month follow-up.	Long term follow up of an RCT	One star	Full paper	UK	63 x 11 to 18 year olds in original trial; 44 in follow-up.

Nijhof, Bleijenberg, Uijterwaal, Kimpen and van de Putte (2012). (See also Nijhof et al, 2011)	Effectiveness of an internet based CBT intervention for adolescents.	FITNET was significantly more effective than control for all primary outcomes after six months including school attendance, absence of fatigue and normal physical functioning. FITNET is a highly effective and accessible intervention for adolescents with chronic fatigue syndrome.	RCT	One star	Abstract	Netherlands	135 participants: 68 assigned to FITNET. Age ranged between 12 and 18 years.
Stulemeijer, de Jong, Fiselier, Hoogveld, Bleijenberg (2005).	Cognitive behavioural therapy for adolescents with chronic fatigue syndrome.	Patients in the therapy group reported significantly greater decrease in fatigue severity and functional impairment and their school attendance increased significantly. CBT is an effective treatment for adolescents with CFS.	RCT	One star	Abstract	Not stated.	71 participants aged 10 to 17 years.

\* Reviews include physiological, pharmacological and psychological interventions. Only psychological interventions have been extracted for this report.

\*\* Looked at adult and child/adolescent participants. Only data on child/adolescents extracted.



## Outcome measures

School attendance was the most consistently used measure of outcome for studies exploring interventions for ME/CFS (Knight et al, 2013; Chalder, Deary, Husain & Walwyn, 2010; Knoop, Stulemeijer, de Jong, Fiselier & Bleijenberg, 2008; Lloyd, Chalder & Rimes, 2012; Nijhof, Bleijenberg, Uiterwaal, Kimpfen and van de Putte, 2011; Stulemeijer, de Jong, Fiselier, Hoogveld, Bleijenberg, 2005) and it was occasionally measured at three, six and 12-month follow-up (Chalder et al, 2010).

A wide range of other measures were identified including exploring levels of fatigue through Fatigue Assessment Scales or a measure of fatigue severity (Chambers et al, 2006; Knight et al, 2013; Knoop et al 2008; Knoop et al, 2007; Nijhof et al, 2011, 2012; Stulemeijer et al, 2005), self-reporting of symptoms, self-reporting of global outcome and satisfaction, and various measures of psychological outcome including Work and Social Adjustment Scale, Hospital Anxiety Depression scale (HADs), Fear questionnaire (Chambers et al, 2006; Knight et al, 2013). Pain reduction was also measured as a predictor of outcome (Knoop et al, 2007). Physical functioning (Nijhof et al, 2011 & 2012) and functional impairment (Stulemeijer et al, 2005) were also measured.

## Interventions and effectiveness

### *Cognitive behavioural therapy (CBT)*

The majority of interventions described in the literature were variations on cognitive behavioural therapy (Chambers et al, 2006; Knight et al, 2013; Knoop et al, 2007; Knoop et al, 2008; Stulemeijer et al, 2005).

Cognitive behavioural therapy based interventions were evaluated in eight of the nine studies reviewed in Knight et al (2013). CBT (face-to-face and internet-based) was found to demonstrate greater improvements in fatigue, school attendance and physical functioning immediately following treatment in three studies and at three months follow-up, when compared with controls. However, there were no significant differences at six and 12-month follow-up (Knight et al, 2013). CBT was associated with a significant positive effect on fatigue, symptoms, physical functioning and school attendance (Chambers et al, 2006).

In other studies (one RCT, a comparative study and three case series studies) CBT based interventions reported positive outcomes in fatigue, school attendance, physical and psychological functioning and quality of life that were maintained at six-month follow-up (Knight et al, 2013).

CBT was associated with no significant change in fatigue severity between post-treatment and follow-up in one study (Knoop et al, 2008) but was associated with a significant further increase in physical functioning and school attendance, with a mean follow-up time of just over two years. Those having CBT were found to be significantly less fatigued and significantly less functionally impaired and had higher school attendance at follow-up (Knoop et al, 2008).

Recovered adolescent CFS patients reported a significant reduction in the severity of their pain compared to non-recovered patients, and they described fewer sites of pain following

CBT. A decrease in fatigue predicted the change in severity of pain (Knoop et al, 2007).

A CBT intervention consisting of 10 sessions of therapy was assessed after five months and patients in the therapy group reported significantly greater reductions in fatigue severity and functional impairment and a significant increase in attendance at school compared to a waiting list control (Stulemeijer et al, 2005).

### **Family-focused CBT**

At six-month follow up, family-focused CBT and a psycho-education control group were associated with similar levels of improvement, but those who had received family-focused CBT were attending school for longer at post-treatment and three month follow-up, leading to conclusions that adolescents with CFS get back to school more quickly after family-focused CBT than psycho-education (Chalder et al, 2010).

In another study, a family-focused CBT intervention (13 x one hour sessions) was compared with four one-hour sessions of psycho-education. Both interventions were associated with an increase in school attendance and although more participants who undertook the family-focused CBT intervention increased their school attendance, the difference was not statistically significant. A greater proportion of patients recovered (defined by fatigue and school attendance) in the CBT group (79%) compared the psycho-education group (64%) but again this was not statistically significant. Family-focused CBT was however associated with significantly improved emotional and behavioural adjustment at 24-month follow-up compared with psycho-education as reported by both the adolescents and parents (Lloyd et al, 2012).

### **Fatigue In Teenagers on the interNet (FITNET)**

Described as the first internet-based therapeutic programme for adolescents with ME/CFS, this intervention is based on cognitive behavioural therapy. FITNET was found to be significantly more effective than usual care for all primary outcomes (school attendance, fatigue severity and physical functioning) at six months with no adverse events reported (Nijhof et al, 2011 & 2012).

### **Narrative self-investigation**

There was some evidence of the effectiveness of 'narrative self-investigation' (Knight et al, 2013). The intervention was not fully described in the review but it is reported that the intervention improved fatigue, physical and psychological functioning in adolescents that was maintained at 10-month follow-up (Knight et al, 2013). There was also evidence that a longer 12-session intervention (as opposed to six sessions) yielded greater improvement (Knight et al, 2013).

## **Conclusions**

The aim of this report was to provide a descriptive overview of the literature on counselling and psychological interventions for children with long-term medical conditions. The literature search uncovered a highly varied evidence base. The search focused on the conditions with the highest quantity and quality of evidence, and the report gives an overview of the literature on multiple conditions, asthma, diabetes and ME/chronic fatigue syndrome.

## General overview

The most common form of long-term medical condition in children across all ages is asthma, which is thought to affect one in seven children in the UK (Smith et al, 2005). This condition was explored in six high quality papers, which included three systematic reviews. It was also explored in the literature on general and multiple conditions. Poorly controlled asthma and 'difficult' asthma are identified as two specific areas of interest as it is estimated that 10% of asthma sufferers fall into these categories but they access a disproportionate (50%) amount of healthcare (Smith et al, 2005).

Children with diabetes are also well represented within the literature: the condition is explored in one systematic review and 14 high quality studies, as well as being represented in the literature exploring multiple conditions. It is estimated that one in 500 children in North America has the condition. Diabetes in adolescents is specifically identified as a problematic area, because it is at this age that young people typically begin to take on self-management of their condition, sometimes with poor effects.

ME/chronic fatigue syndrome was well represented within the literature, perhaps at a level disproportionate to its estimated prevalence (.0006% to 2% (Knight et al, 2013)). There were two systematic reviews and five high quality papers exploring the condition, but ME/CFS was not represented in the literature on multiple conditions. This possibly reflects some issues specific to the literature on ME/CFS:

- Some papers explore all aspects of treatment for ME/CFS, including physiological and pharmacological treatments, although only the psychological aspects have been extracted for this report. This suggests that there are broader questions around the management of the condition.
- Most papers explore both adult and child populations, so the issues are not necessarily specifically child-focused. It is worth noting that unlike the other conditions, the treatment recommendations for ME/CFS are translated from research into adults alongside clinical consensus. This is specifically avoided in the other conditions because the populations are thought to be so different (Knight et al, 2013).
- The population represented in the literature is broadly adolescent young people. Whether this indicates that ME/CFS is more prevalent in adolescence or whether this reflects when diagnosis occurs is unknown.
- There is an added complexity in how ME/CFS is diagnosed, and at least two different criteria for diagnosis are represented in the literature.

Generally, long-term health conditions in children are thought to have doubled in the last 20 years and are described as having a high prevalence (Eccleston et al, 2012). In the literature on multiple conditions, which includes three systematic reviews, a wide range of conditions are represented, including asthma, diabetes, rheumatoid conditions, pain conditions, sickle cell, HIV and epilepsy. Long-term medical conditions are understood to be particularly difficult for children and young people because their management involves regular, daily medical, dietary and physical tasks often within highly complex regimens.

### **Psychological therapies for children with long-term medical conditions**

Treatment adherence emerges as the focus of psychological therapies for children with long-term chronic medical conditions. Not adhering to treatment effectively renders a condition untreated, which leaves the child or young person at risk of complications or even death. Individuals with poorly managed diseases make disproportionate use of healthcare resources. Treatment adherence is measured in large variety of ways, some of which are condition specific measures (e.g. lung function in asthma), and include hospital admissions, appointment attendance, school absence, and self-reporting on behaviour. For asthma and diabetes, treatment adherence appears the primary measure of outcome throughout the literature, for ME/CFS, school attendance is the most consistently measured outcome.

The interventions explored in the literature are highly variable and were often condition specific. Psycho-educational and psychosocial interventions tend to be multi-faceted and incorporate condition specific education with behavioural approaches to influence treatment adherence. CBT-based interventions were particularly prevalent for children with ME/CFS and there is a small body of evidence suggesting that relaxation-based interventions can be effective with asthma sufferers.

There are a range of family-focused interventions for populations with a child with chronic illnesses represented in the literature, which are based on multisystemic therapy, CBT or problem solving techniques. There is evidence of home-based and telephone delivered therapies being used with families, and of condition specific internet-based programmes. Some interventions extend beyond the family and incorporate the community around the child (e.g. school).

While there is mention of other therapies – art therapy for children with asthma, and narrative self-investigation for young people with chronic fatigue syndrome - little evidence was found of the use of general counselling and psychotherapy with children with long-term medical conditions and their families, within the literature.

### **Effectiveness of psychological therapies for children with long-term medical conditions**

Overall, while there is evidence of the effectiveness of a wide range of interventions for children with long-term medical conditions and their families, no specific intervention emerges as most effective. This is in part due to the diversity of interventions being offered, but also because the diversity of outcome measures does not allow for the meta-analysis of results, and the poor quality of studies. No intervention was found to be effective across all outcome measures. There is a lack of evidence of the long-term effectiveness of interventions, which is not only due to a lack of follow-up studies, but also, where evidence exists, outcomes were not always sustained in the long term. The following summary is an attempt to draw together conclusions across all conditions, and highlight where there are interventions specific to a condition.

#### ***Implications for practice***

- Psycho-education and multi-faceted interventions
  - Interventions that combined behavioural and educational elements or interventions defined as behavioural or multi-faceted were found to be more likely than educational interventions alone to improve adherence to treatment outcomes, though there is less evidence of this effect being

maintained over time (Clarke & Calam, 2012; Couch et al, 2008; Dean et al, 2010; Eccleston et al 2012; Kahana et al, 2008; Murphy et al, 2006; Ng et al, 2008; Smith et al, 2005).

- CBT and behavioural interventions
  - CBT and behavioural therapy were found to be effective with some outcomes (Silverman et al, 2003; Yorke et al, 2005).
  - There is some evidence of the effectiveness of CBT-based interventions and problem-solving interventions for parents (Eccleston et al, 2012).
  - CBT was the most prevalent intervention for young people with chronic fatigue syndrome and there is evidence of its effectiveness across various outcome measures (Chambers et al, 2006; Knight et al, 2013), but there were mixed results at follow-up (Knight et al, 2013; Knoop et al, 2008). There is some evidence for the effectiveness of a family-focused CBT intervention (Chalder et al, 2010) with some evidence of continued improvement at follow-up (Lloyd et al, 2012).
  - CBT has the strongest evidence base for psychological interventions for children and young people with ME/chronic fatigue syndrome.
- Family-focused interventions
  - A range of family therapy interventions demonstrated more promising effects on health outcome measures than educational interventions (McBroom & Enriquez, 2009; Savage et al, 2010).
  - Family-focused interventions across all conditions appeared to demonstrate some effectiveness with some outcomes (Burton, 2010; Chalder et al, 2010; Eccleston et al, 2012; Ellis, Frey et al, 2005; Ellis, Naar-King et al, 2005; Ellis et al, 2012; Ellis, Naar-King et al, 2007; Ellis, Templin, et al, 2007; Ellis, Yopp et al, 2007; Harris et al, 2009; Kahana et al, 2008; Lehmkuhl et al, 2010; McBroom & Enriquez, 2009; Ng et al, 2008, Savage et al, 2010), but with some mixed results (Eccleston et al, 2012).
- Other interventions
  - There is a lack of research, and therefore lack of evidence of effectiveness, for other kinds of counselling and psychotherapy for children with long-term medical conditions, limited to the following interventions identified.
    - Relaxation-based interventions were found to have an effect on some measures and outcomes for children with asthma (Kappor et al, 2010; Yorke et al, 2005).
    - Art therapy was found to be effective at decreasing anxiety and increasing quality of life for asthma sufferers (Beebe et al, 2010; Clarke & Calam, 2012).
    - Narrative self-investigation was found to have some evidence of effectiveness for children with ME/CFS (Knight et al, 2013).
- Internet or telephone based interventions
  - There is evidence for the effectiveness of internet-based games (Kahana et al, 2008), internet (Nijhof et al, 2011 & 2012) or telephone-based interventions (Lehmkuhl et al, 2010) for children and their families with long-term medical conditions, with some promising results (Lehmkuhl et al, 2010) and some evidence of effectiveness (Nijhof et al, 2011 & 2012).
- The lack of evidence of the sustained effect of interventions leads some authors to

suggest that psychological interventions for children with long-term medical conditions and their families should be integrated into their ongoing clinical care (Kahana et al, 2008).

### Implications for research

- The diversity of interventions and outcome measures makes it difficult for researchers to pool results and conduct meta-analyses. There is a call for more consistent use of outcome measures (Beale, 2006; Couch et al, 2008; Dean et al, 2010; Eccleston et al, 2012; Ellis, Frey et al 2005; Harris et al, 2009; Kahana et al, 2008; Knight et al, 2013; Smith et al, 2005; Yorke et al 2005) and to develop patient focused measures (Smith et al, 2005).
- Poor studies are also blamed for the lack of conclusive evidence so there is a call for more high quality randomised controlled trials (Beale, 2006; Dean et al, 2010; Eccleston et al, 2012; Kahana et al, 2008; Smith et al 2005; Yorke et al, 2005) with larger sample sizes and better described interventions, illness groups and outcome measures (Dean et al, 2010; Eccleston et al, 2012; Kahana et al, 2008).
- There is a need to identify the active ingredients in behavioural and multi-component interventions in future research (Kahana et al, 2008).
- There is a need for more research into psychosocial interventions and more longitudinal studies (Kahana et al, 2008).
- Many authors call for more research into outcomes for patients in single parent families, families from ethnic minorities or low socio-economic groups and to explore these as mediating factors on health outcome (Couch et al, 2008; Ellis, Frey et al, 2005; Harris et al, 2009) and for research into interventions in community settings (Smith et al, 2005).
- There is no evidence for the use of, or effectiveness of generic counselling and psychotherapy for children with long-term medical conditions, and so more research is needed in this area.

### Implications for policy

- There is a lack of evidence of the long-term efficacy of interventions. This may mean that effective interventions like CBT may need to be considered in the long-term care of children and adolescents with CFS/ME and integrated into clinical management (Knight et al, 2013) which may have cost implications for healthcare delivery.
- The issue of how psychological interventions are funded was only touched upon within the literature. Some interventions were not designed to be time-limited, and therefore may not be eligible to be paid for by health insurance. While this is an issue perhaps specific to the US, in the UK the capacity of the NHS to fund ongoing long-term interventions may be difficult, therefore the cost effectiveness of psychological interventions should be considered.
- The interventions described in this review are required to be delivered by trained professionals which may have implications for funding requirements and cost effectiveness (Chambers et al, 2006).

## References

- BACP (2010) *What is counselling and psychotherapy?*  
<http://www.bacp.co.uk/crs/Training/whatiscounselling.php>. Retrieved 13/10/2014.
- Beale, I., (2006). Scholarly literature review: Efficacy of psychological interventions for pediatric chronic illnesses. *Journal of Pediatric Psychology* 31(5): 437-51.
- Beebe, A., Gelfand E. and Bender, B. (2010). A randomized trial to test the effectiveness of art therapy for children with asthma. *Journal of Allergy and Clinical Immunology* 126(2): 263-6, 266 e1.
- Burton, M., (2010). Supporting adolescents who have a sibling with a life-threatening illness: An exploratory study. *Counselling & Psychotherapy Research*, 10(4), 316-321.
- Clarke, S. A. and Calam R. (2012). The effectiveness of psychosocial interventions designed to improve health-related quality of life (HRQOL) amongst asthmatic children and their families: a systematic review. *Quality of Life Research* 21(5): 747-64.
- Chalder, T., Deary, V., Husain, K. & Walwyn, R. (2010). Family-focused cognitive behaviour therapy versus psycho-education for chronic fatigue syndrome in 11 to 18-year-olds: a randomized controlled treatment trial. *Psychological Medicine* 40(8): 1269-79.
- Chambers, D., Bagnall, A., Hempel, S. and Forbes, C. (2006). Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/myalgic encephalomyelitis: an updated systematic review. *Journal of the Royal Society of Medicine* 99(10): 506-20.
- Couch, R., Jetha, M., Dryden, D., Hooton, N., Liang, Y., Durec, T., Sumamo E., Spooner, C., Milne, A., O’Gorman, K. and Klassen, T. (2008). Diabetes education for children with type 1 diabetes mellitus and their families. *Evidence Report Technology Assessment (Full Rep)*(166): 1-144.
- Dean, A., Walters, J. and Hall, A. (2010). A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness. *Archives of Disease in Childhood* 95(9): 717-23.
- Diabetes UK (2014). *Diabetic Ketoacidosis (DKA)*  
[http://www.diabetes.org.uk/Guide-to-diabetes/Complications/Diabetic\\_Ketoacidosis/?gclid=CJvQkoLs4MACFSITwwodBGEAgw](http://www.diabetes.org.uk/Guide-to-diabetes/Complications/Diabetic_Ketoacidosis/?gclid=CJvQkoLs4MACFSITwwodBGEAgw) . Retrieved 14/9/14.
- Eccleston, C., Palermo, T., Fisher, E. and Law, E. (2012). Psychological interventions for parents of children and adolescents with chronic illness. *The Cochrane Database of Systematic Reviews* 8: CD009660.
- Ellis, D., Frey, M., Naar-King, S., Templin, T., Cunningham, P. and Cakan, N. (2005). The effects of multisystemic therapy on diabetes stress among adolescents with chronically poorly controlled type 1 diabetes: findings from a randomized, controlled trial. *Pediatrics* 116(6): e826-32.
- Ellis, D., Naar-King, S., Frey, M., Templin, T., Rowland, M. and Cakan, N. (2005). Multisystemic treatment of poorly controlled type 1 diabetes: effects on medical resource utilization. *Journal of Pediatric Psychology* 30(8): 656-66.
- Ellis, D., Naar-King, S., Chen, X., Moltz, K., Cunningham, P. and Idalski-Carcone, A. (2012). Multisystemic therapy compared to telephone support for youth with poorly controlled diabetes: findings from a randomized controlled trial. *Annals of Behavioural Medicine* 44(2): 207-15.

Ellis, D., Naar-King, S., Templin, T., Frey, M. and Cunningham, P. (2007). Improving health outcomes among youth with poorly controlled type I diabetes: the role of treatment fidelity in a randomized clinical trial of multisystemic therapy. *Journal of Family Psychology* 21(3): 363-71.

Ellis, D., Templin, T., Naar-King, S., Frey, M., Cunningham, P., Podolski, C. and Cakan, N. (2007). Multisystemic therapy for adolescents with poorly controlled type I diabetes: Stability of treatment effects in a randomized controlled trial. *Journal of Consulting and Clinical Psychology* 75(1): 168-74.

Ellis, D., Yopp, J., Templin, T., Naar-King, S., Frey, M., Cunningham, P., Idalski, A. and Niec, L. (2007). Family mediators and moderators of treatment outcomes among youths with poorly controlled type 1 diabetes: results from a randomized controlled trial. *Journal of Pediatric Psychology*, 32(2): 194-205.

Guyatt, G. H., Sackett, D. L., Sinclair, J. C., Hayward, R., Cook, D. J., Cook, R. J., ... and Wilson, M. (1995). Users' guides to the medical literature IX. A method for grading health care recommendations. *Jama*, 274(22), 1800-1804.

Hafkamp-de Groen, E., Mohangoo, A. D., de Jongste, J. C., van der Wouden, J. C., Moll, H. A., Jaddoe, V. W., et al. (2010). Early detection and counselling intervention of asthma symptoms in preschool children: study design of a cluster randomised controlled trial. *BMC Public Health*, 10, 555.

Harris, M. A., Freeman, K. A. and Beers, M. (2009). Family therapy for adolescents with poorly controlled diabetes: initial test of clinical significance. *Journal of Pediatric Psychology*, 34(10): 1097-107.

Kahana, S., Drotar, D., and Frazier, T., (2008). Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology* 33(6): 590-611.

Kapoor, V., Bray, M. and Kehle, T. (2010). School-based intervention: Relaxation and guided imagery for students with asthma and anxiety disorder. *Canadian Journal of School Psychology* 25(4): 311-327.

Knight, S. J., Scheinberg, A. and Harvey A. (2013). Interventions in pediatric chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. *Journal of Adolescent Health* 53(2): 154-65.

Knoop, H., Stulemeijer, M., de Jong, L., Fiselier, T., and Bleijenberg, G. (2008). Efficacy of cognitive behavioral therapy for adolescents with chronic fatigue syndrome: long-term follow-up of a randomized, controlled trial. *Pediatrics* 121(3): e619-25.

Knoop, H., Stulemeijer, M., Prins, J., van der Meer, J. and Bleijenberg, G. (2007). Is cognitive behaviour therapy for chronic fatigue syndrome also effective for pain symptoms? *Behaviour Research and Therapy* 45(9): 2034-2043.

Lanzarote Fernandez, M.D., and Torrado Val, E. (2009). Counselling and family psychotherapy with children and adolescents with chronic illness. *Apuntes de Psicología*, 27(2-3), 457-471.

Lehmkuhl, H., Storch, E., Cammarata, C., Meyer, K., Rahman, O., Silverstein, J., Malasanos, T. and Geffken, G. (2010). Telehealth behavior therapy for the management of type 1 diabetes in adolescents. *Journal of Diabetes Science and Technology*, 4(1): 199-208.

Lloyd, S., Chalder, T., and Rimes K., (2012) Family-focused cognitive behaviour therapy versus psycho-education for adolescents with chronic fatigue syndrome: Long-term follow-up of an RCT. *Behaviour Research and Therapy* 50(11): 719-725.

McBroom, L., and Enriquez M., (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator*, 35(3): 428-38.



- Morison, J., Bromfield L., and Cameron H., (2003). A Therapeutic Model for Supporting Families of Children with a Chronic Illness or Disability. *Child and Adolescent Mental Health*, 8(3), 125-130.
- Murphy, H., Rayman, G. and Skinner, T. (2006). Psycho-educational interventions for children and young people with Type 1 diabetes. *Diabetic Medicine* 23(9): 935-43.
- Nansel, T., Iannotti R. and Lui, A. (2012). Clinic integrated behavioural intervention for families of youth with type 1 diabetes: randomized control trial. *Pediatrics* 129(4): e866-73.
- Naar-King, S., Ellis, D., Idalski, A., Frey, M. and Cunningham, P. (2007). Multisystemic Therapy Decreases Parental Overestimation of Adolescent Responsibility for Type 1 Diabetes Management in Urban Youth, *Families, Systems and Health*, Vol. 25, No. 2, 17.
- Ng, S., Li, A., Vivian, W., Lou, I., Tso, P., Wan Y. and Chan, D. (2008). Incorporating family therapy into asthma group intervention: A randomized waitlist-controlled trial. *Family Process* 47(1): 115-130.
- Nijhof, S., Bleijenberg, G., Uiterwaal, C., Kimpen J. and van de Putte, E. (2012) Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): A randomised controlled trial. *The Lancet* 379(9824): 1412-1418.
- Nijhof, S. Bleijenberg, G., Uiterwaal, C., Kimpen J., and van de Putte, (2011). Fatigue in teenagers on the internet-The FITNET Trial. A randomized clinical trial of web-based cognitive behavioural therapy for adolescents with chronic fatigue syndrome: Study protocol. *BMC Neurology* 11.
- Savage, E., Farrell, D., McManus V. and Grey, M. (2010). The science of intervention development for type 1 diabetes in childhood: systematic review. *Journal of Advanced Nursing* 66(12): 2604-19.
- Silverman, A., Hains, A., Davies, H. and Parton, E. (2003). A cognitive behavioral adherence intervention for adolescents with type 1 diabetes. *Journal of Clinical Psychology in Medical Settings* 10(2): 119-127.
- Smith, J., Mugford, M., Holland, R., Candy, B., Noble, M, Harrison, B., Koutantji, M, Upton, C. and Harvey, I. (2005). A systematic review to examine the impact of psycho-educational interventions on health outcomes and costs in adults and children with difficult asthma. *Health Technology Assessment*, 9(23): iii-iv, 1-167.
- Stulemeijer, M., de Jong, L., Fiselier, T., Hoogveld, S. and Bleijenberg, G. (2005). Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: Randomised controlled trial. *British Medical Journal* 330(7481): 14.
- Thompson, R., Delaney, P., Flores, I., and Szigethy, E. (2011). Cognitive-behavioral therapy for children with comorbid physical illness. *Child and Adolescent Psychiatric Clinics of North America*, 20(2): 329-48.
- Yorke, J., Fleming, S., and Shuldham, C. (2005). Psychological interventions for children with asthma. *Cochrane Database Systematic Review* (4): CD003272.

April 2015