

PSYCHOLOGICAL SUPPORT

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CANCER SUPPORT**

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Psychological support

Acute psychological distress is an understandable reaction when someone is given a diagnosis of cancer, which will change their future forever.

Most people react with numbed shock and disbelief, followed by anxiety, anger, and sadness. The NHS Cancer Plan¹ highlighted the fact that the diagnosis and treatment of cancer can have a devastating impact on the quality of patients' lives and those of their families and carers.

The impact of cancer is related to four main factors:

- The existential threat of the disease.
- Its psychosocial consequences: such as the potential effects on employment, family role and social life.
- The consequences of the morbid disease process, such as pain, fatigue and shortness of breath.
- The treatment and its effects, such as nausea, hair loss, body changes resulting from surgery, or loss of fertility.



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Coping with this impact means an intense period of adjustment to the challenges faced. It also means coming to terms with a perceived loss of control and living with uncertainty about the future.

In most cases and with the right support, a person's acute psychological reaction to diagnosis reduces within a few weeks. This happens as they learn, sometimes painfully and slowly, to come to terms with their disease and its impact on their life. They can be helped to make this adjustment through using their own coping strategies, and through the emotional and



practical support of their family, friends and the medical team.

That adjustment can change over time as they cope with different treatment demands. They may begin to understand the extent of permanent disabilities and ultimately, changes in the future of certain relationships and the long-term uncertainty of their future. Added to this, they may also be coping with financial challenges, employment impacts, childcare demands and changes to their role within the family.

Some people continue to struggle to adjust, and experience significant emotional and psychological effects of cancer and its treatment. These effects can include depression, anxiety, memory problems,

difficulty concentrating, sexual problems and reduced confidence in social situations. This distress is associated with a range of harmful outcomes, including amplification of physical symptoms, poorer levels of functioning, adverse impact on carers, an enhanced desire for death, reduced adherence to cancer treatment, and probable reduction in life expectancy. It also vastly increases utilisation of constrained healthcare resources.²

Patients and their loved ones are likely to benefit from some form of professional psychological support, whether they experience mild and transient emotional turmoil or severe depression. Around one in four patients will require expert psychological assessment and intervention as a result of their diagnosis. One in ten will require specialist support from a clinical psychologist or psychiatrist.² The costs of such support are often far lower than the costs that would result from their absence.

Psychological care services

Psychological services should be given equal priority alongside diagnosis and treatment. They should help the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. Best practice standards recommend promoting psychological well-being and preventing the onset of more serious mental ill health.

A good psychological care pathway should empower patients to take greater control of what happens to them and support them to self-manage their needs. Simultaneously, it should provide access to additional coping strategies and resources, thereby increasing psychological and physical resilience throughout treatment and beyond. It should provide focused preventative interventions to people who

are more vulnerable to distress, as well as a reactive service that supports those who are coping with significant psychological distress, including depression and anxiety. Psychological support services need to address the full range and severity of psychological problems associated with cancer, including:

- adjustment difficulties
- anxiety
- depression
- problems with personal relationships, including communication with health professionals
- psychosexual and body image difficulties
- alcohol and drug-related problems
- personality disorder
- deliberate self-harm
- psychotic illness and organic brain syndromes.

The four level model

The National Institute for Health and Care Excellence (NICE) issued guidance in 2004 on the provision of supportive and palliative care for adults with cancer.³ It recommends a four level model for psychological support services for all patients with cancer and their families. This is underpinned by recognition that patients and carers can often assess their own emotional status and meet their own needs for support.

Psychological support can be separated into two distinct categories, provided by:

- professionals with some training in assessment and frontline interventions of psychological problems, but who are not mental health or psychological support professionals (levels one and two)
- trained mental health or psychological support professionals (levels three and four).

The table overleaf shows the NICE recommendations for assessment and intervention at these levels.

NICE recommended model of professional psychological assessment and support³

Professional level	Group of professionals	Assessment	Intervention
One	All health and social care professionals.	Recognition of psychological needs.	Effective information giving, compassionate communication and general psychological support.
Two	Health and social care professionals with additional experience.	Screening of psychological distress.	Psychological techniques such as problem solving.
Three	Trained and accredited professionals.	Assessment of psychological distress and diagnosis of some psychopathology.	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework.
Four	Mental health specialists.	Diagnosis of psychopathology.	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT).

Level one

All professionals supporting people affected by cancer should offer high-quality information to empower them. This information can enhance people's understanding, and their ability to participate in key decisions about how their cancer is managed. Information also facilitates adjustment, prevents unnecessary anxiety, and contributes to informed consent, all at a relatively low cost.

Clinicians should also provide general emotional support, based on skilled communication and compassionate listening, as a routine part of their practice. They also need to be able to skilfully elicit health beliefs, support decision-making, mobilise coping and promote adherence to treatment plans.

Level two

Professionals guided by the holistic needs assessment (HNA) need to be able to formally detect and assess psychological distress. Level two clinicians should also be able to: offer focused interventions designed to enhance self-care skills and perception of control; improve ability to adjust to life situations; problem solve; and provide enhanced psychological information. In many cases, the psychological distress and concerns identified can be addressed and resolved, increasing the patient's ability to cope on a day-to-day basis. However, they may need to be offered a referral to specialised psychological care services appropriate to their needs and preferences.

Level three

Psychological care professionals (counsellors or therapists) should offer targeted interventions to enhance a person’s psychological well-being, by enabling them to adjust to their situation. Or they should work with the person using psychological therapy – such as solution-focused or cognitive therapy – to manage more mild to moderate levels of depression and anxiety.

Level four

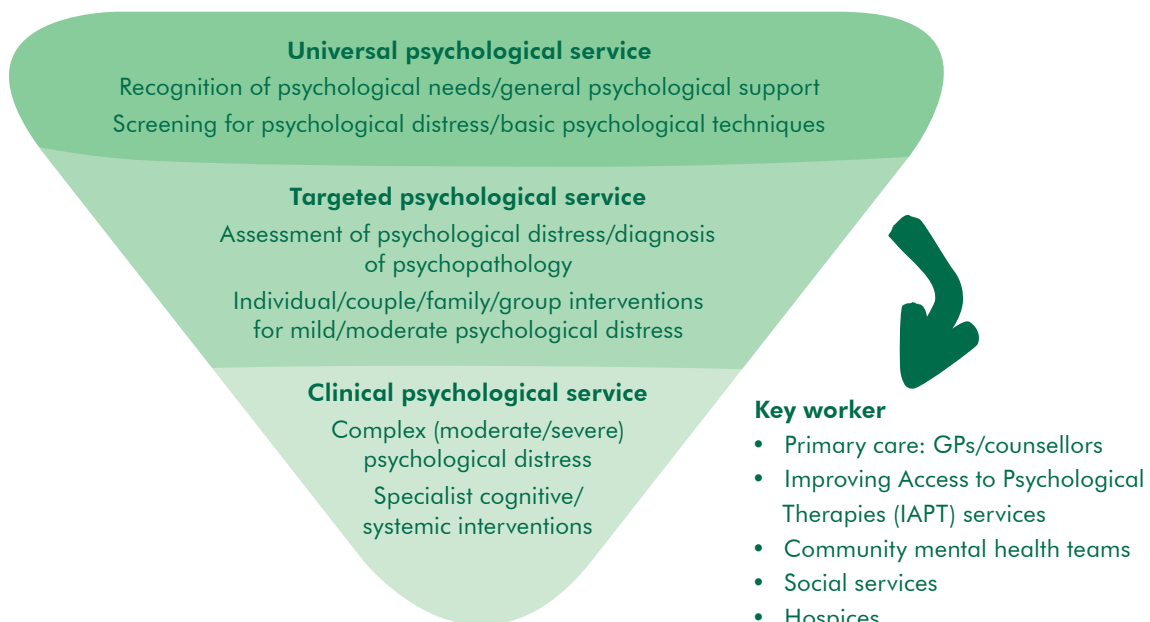
Professionals, such as clinical psychologists, are trained to manage complex psychological health needs and provide specialist care for people with a diagnosis of pre-existing severe mental health illness that has been exacerbated by cancer.

The integrated pathway to success

A successful psychological care pathway should influence, and be embedded within, a person-centred care pathway. This is a pathway where patients receive the right services, at the right time and from the right people. It is a pathway that empowers people to support their own holistic needs, including psychological needs, from diagnosis to living with and beyond cancer.

The preferred model is to embed psychological services within the setting of active treatment or palliation (at hospitals and hospices), but integrated with the work of community professionals providing psychological care.

Pyramid of psychological support³



Studies have shown that 65% of people diagnosed with cancer will need the 'universal' services shown in the diagram on the previous page (levels one and two). 25% will require more targeted interventions (level three) and 10% will struggle with significant psychological distress and require level four services such as clinical psychology. This model ensures cost-effective use of these more constrained resources.³

Clinical psychology

Clinical psychologists have the skills to enhance psychological well-being. They are able to understand and minimise the psychological impact of acute and chronic health conditions and can provide interventions to 'treat' mental health issues.

A skilled clinical psychologist can offer skills that impact on each level of the four level model. This can range from developing psychological resources for patients and families, to training clinicians in compassionate communication, detecting psychological distress and offering psychological interventions. They can then support the application of training for colleagues within clinical practice, through ongoing consultation with multidisciplinary teams (MDTs) and by offering clinical supervision to level two practitioners.

There is general recognition that those providing psychological care need to be properly supervised, either in one-to-one situations or in groups, peer groups and work teams. Research suggests that without ongoing supervision, level two trained individuals will not maintain their skills, as this is not their core profession.⁴ Evidence also suggests when professionals are not trained in communication and

psychological skills needed to carry out a comprehensive HNA, only 3% of co-morbid psychological distress detected results in an evidence-based psychological intervention.²

Clinical psychologists can also develop, deliver and supervise focused psychological interventions such as therapy and groups at level three, as well as complex interventions at level four. They are trained to apply psychological interventions systemically within MDT and in-patient environments that support an individual's well-being. They are also skilled at understanding the impact of cancer on a family, including children's and young people's psychological well-being.

Clinical psychology can also support clinicians' psychological well-being when working in such an emotive and demanding clinical area. It does this by offering supervision and support to enhance their own skills in self-care, manage occupational stress and to recognise and prevent 'burn out'. When the psychological needs of staff are adequately met, it enhances their ability to provide good-quality care.

In summary, clinical psychologists can positively influence the design of care pathways and the approach of clinicians across all cancer services. They can ensure there is a coherent psychological care pathway throughout the person-centred care pathway, which supports patients, their families and professional psychological well-being.

A positive outcome at a reduced cost

When the psychological needs of people living with cancer and those close to them are met during treatment, they feel empowered to take control of their lives and cope with the uncertainty of their future. The psychological impact of cancer is not just in terms of distress, but relates to engagement with and utilisation of healthcare.

Better psychological outcomes offer a significant economic saving by increasing adherence to treatment, reducing take-up of additional services, reducing bed days and improving decision-making about treatment choice. This creates a much higher rate of return than the investment in the services set up. Estimates indicate that having professional psychological services embedded within adult cancer services can save up to 20% of healthcare utilisation costs.⁵

In their 2004 review, Carson and Bultz wrote: 'The literature review clearly supports the notion that psychosocial interventions are not only effective, but also economical'. They refer to the 'usually overlooked long-term cost savings that may be accrued to overburdened health-care systems'.⁵

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Evidence base

There is strong evidence demonstrating the benefits of interventions with people who experience psychological distress.



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Prevalence of psychological distress

Psychological distress occurs on a spectrum from mild to severe, the latter of which is known to have significant consequences. Neurobiological research is adding to knowledge that cancer and its treatment affect neuroimmune functioning, which can trigger emotional consequences – depression in particular – and thus altered mood.¹ Whether the cause is biological or psychological, mood disturbance can be effectively treated once

identified. The observation that for up to 73% of cancer patients with clinical depression, the depression goes untreated, should raise serious doubt that screening for distress is routinely undertaken in some services.²

As already noted, the 2004 NICE guidance states that 25% of patients require targeted professional intervention to support distress associated with initial diagnosis.³ For the year following diagnosis, prevalence of symptoms requiring specialist interventions is 10%, and it is up to 15% in those suffering advanced disease. NICE guidelines are supported by two key meta-analyses^{4,5} showing a need for such targeted treatment of distress in up to 38.2% of patients.

In a large cross-sectional study, 20,000 patients in a Scottish specialist cancer service were routinely screened for clinical depression.² This robust study indicated higher prevalence of depression than in the general population: 13.1% for lung cancer, 10.9% for gynaecological cancer, 9.3% for breast, 7% for colorectal, and 5.6% for genitor-urinary cancers. Greater vulnerability to depression was observed for younger patients, those in greater social deprivation, and women.

Despair, depression, feelings of hopelessness, lack of social support, and anxiety all suggest a higher vulnerability to suicidal feelings and actual self-harm.⁶ Cancer patients are at an increased risk of taking their own lives compared to the general population.⁷ A US study suggests cancer is the only

health condition significantly associated with suicide: between 8.5% and 12% of patients experienced thoughts of self-harm or desire for death.⁶ An effective psychological care pathway is essential to enable good screening and multi-disciplinary management of self-harm risk, requiring advanced communication skills in staff, and including a crisis response process which guides the care of patients at risk of self-harm and suicide.

Consequences and costs of distress

A recent Macmillan report into developing adult psychological services in cancer care provides an excellent summary of research in this area, suggesting that additional costs to the NHS for all long-term conditions including cancer fall between £8 and £13 billion.¹⁰

Emotional distress and mood disorders have implicit or knock-on financial costs as well as direct costs. These include poorer treatment adherence, reduced pain and symptom tolerance, higher mortality, reduced immunity through the effect of psychological stress, poorer levels of functioning, amplification of physical symptoms, and impact on carers. Without appropriate psychological intervention, these can result in increased use of healthcare resources such as contacts with CNSs, and GP and emergency visits.^{8,9}

Examples include conditions such as needle phobia, or eating phobias, which may occur during treatment for head and neck cancer or when suffering nausea during other treatments. Although rare, these difficulties may result in treatment refusal and enormous distress. They can interfere significantly with recovery and morbidity, and thus result in more complicated treatment with associated costs.

Economic benefits of psychological services at all levels of the NICE guidance

Estimates of cost benefits suggest savings up to 20% when psychological services and holistic psychologically-informed care pathways exist within cancer care.¹¹

In addition to the benefits of direct psychological interventions with individuals or groups of patients, some benefit also derives from enhanced staff skills as a result of psychological consultation and training, and the positive effects on patient care when staff feel fully emotionally and psychologically supported.¹⁰

Clinical effectiveness of interventions at levels one and two

There is growing evidence of effectiveness of interventions at all levels which include a range of types of interventions, delivered by staff with varying specialist skills.¹¹ A recent Cochrane review looked at psychological interventions, mainly at levels one and two.¹² No changes in depression or anxiety were observed, but small improvements in general psychological distress levels were noted for newly-diagnosed people. Participants were not screened for distress and were thus a mixed group.

For patients with haematological malignancies, stem cell transplantation is a particularly burdensome treatment with considerable psychological consequences, including post-traumatic symptoms in up to 25% of patients.⁸ A review of 11 studies with transplant patients showed a small but beneficial effect of interventions including cognitive behavioural therapy (CBT), with maintenance of this effect up to a year post-transplant. The most effective interventions were those with a substantial psychological component.⁸

Clinical effectiveness of interventions at levels three and four

In order to deliver effective interventions targeted at those with high levels of distress, screening with tools such as a holistic needs assessment is crucial. When referred to clinical psychologists, patients are offered targeted psychological therapies which have a strong evidence base in mental health settings and for a range of other health conditions.

Psychological treatments for phobias have long been known to be particularly effective, and such treatments will have a major impact on patients whose anxieties and phobias interfere with completing treatment. Evidence of a positive effect on depression has been noted for CBT, relaxation and stress management, behavioural activation, couple and family systemic therapy, and a range of psychotherapies in palliative care.¹³ Effects were observed at early, mid and palliative stages.

The section on Acceptance and Commitment Therapy (ACT) will review the evidence for this particular therapy.

Summary

Documents published by the London Cancer Alliance¹⁴ and Macmillan¹⁰ give guidance for professionals seeking to establish these services where they do not already exist, and provide advice on how they can interface with multidisciplinary team work.

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Acceptance and Commitment Therapy

The Acceptance and Commitment Therapy (ACT) model can help people affected by cancer regain a sense of control.

A cancer diagnosis, and living with and beyond it, can elicit many distressing thoughts and feelings. People often describe that they feel as though they have 'lost control' and experience many frightening worries such as 'What will happen to me and my family?', 'How will I cope?', 'Will the cancer come back?' and 'Will I die?'. Adjusting to the impact on many areas of their life can be a difficult and ongoing task. Many people understandably feel that their survival is threatened, as well as their sense of normality and their predicted or expected future.

As humans, our usual way to react to such a threat is with our innate 'fight, flight or freeze' survival response. We have evolved to try to get rid of threats. The example of being faced with a hungry tiger comes to mind – we automatically run away, fight or hide in order to stay safe. This system also then enables us to learn from past experiences and predict future ones, to prepare ourselves for what may come and plan how to avoid any potential threats. This mechanism helps the world to feel more predictable, which increases our sense of control and safety.¹ Our minds have therefore evolved to think the way they do; to worry, plan, problem-solve and predict the negative. Our bodies also respond by eliciting a range of feelings, such as anger, fear, sadness, guilt and insecurity – each telling us something important about the situation we are facing and the potential impact on the things which we value. Therefore, in essence our thoughts and feelings are understandable natural reactions and are not controllable.

Yet we are often caught up in an expectation that we 'should' be happy, think positively and be able to get rid of unpleasant thoughts and feelings.

When faced with the scary uncertainty of cancer, people understandably rely on these automatic reactions to try to protect themselves and those around them from distress. Ultimately, they can end up feeling very stuck when the thoughts and feelings do not go away in the long term. To try to cope, they may isolate themselves from the people and activities that they care about to avoid potential triggers for the distress. They may keep busy so they don't have time to think or feel. Or they may become caught up in the painful awareness that things have changed and they are now further away from their ideal reality. People often struggle and criticise themselves for not being happy or for feeling upset. In particular, this struggle often appears to be most prevalent after treatment has finished, when people often feel a sense of abandonment by the healthcare team, a heightened sense of responsibility over their own safety from cancer and an expectation that they should return to 'life as normal'.

This is where the Acceptance and Commitment Therapy (ACT) model comes into its own.^{1, 2, 3, 4}



Further information

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The ACT model

The ACT model is not about challenging, changing or reducing distress; thoughts and feelings are not viewed as irrational or abnormal. ACT recognises that life is painful and suffering is universal.

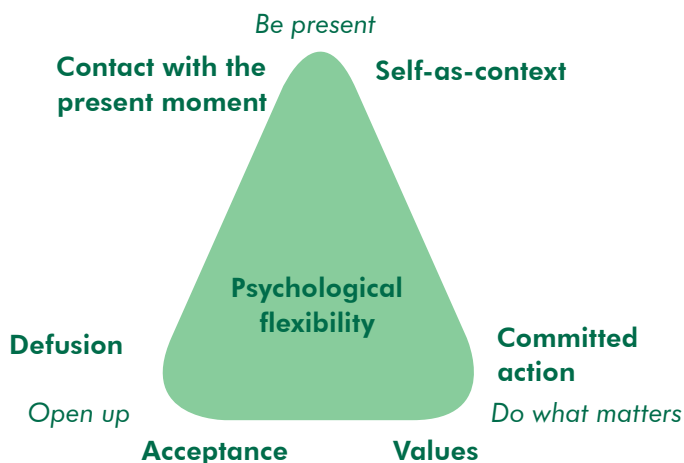
It is based around six core therapeutic processes, which can be grouped into three areas (see Figure 1). Building on these processes enables people to increase their psychological resilience by dropping the struggle with their thoughts and feelings. The emphasis instead lies on developing the ability to open up to and allow thoughts and feelings to be as they are. This frees up time, energy and mental space to enable the person to more consciously choose which action is most workable in that moment, helping them to connect with relevant and meaningful personal values. Therefore, this can enhance their sense of well-being, vitality and quality of life in the face of distress. This model is becoming widely accepted as an effective psychological approach within health-care settings.^{5,6}

Our Living with Uncertainty Group

Alongside other group interventions that our Psychology Within Cancer Services team has developed, including fatigue management, anxiety management and mindfulness, we were particularly interested in developing an ACT-based group. As well as the growing evidence base for the use of ACT in cancer settings specifically^{6,7,8} the model seemed a good fit with the struggles associated with living with the impact of cancer. The process of sharing these experiences within a group intervention also helps to normalise difficult thoughts/feelings and offers a sense of feeling understood.

The group is spread over four two-hour sessions co-facilitated by two members of the Clinical Psychology and Counselling service and is held in a community setting, away from the hospital environment and 'patient role'. Each session focuses on particular ACT concepts, which are explored using experiential exercises and reflection time throughout.

Figure 1: The ACT triflex³



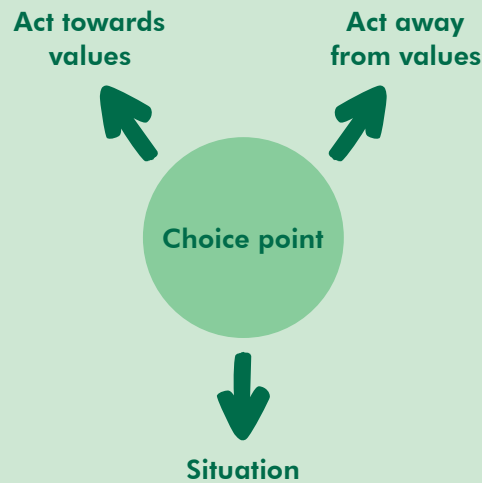
How our ACT sessions are run

Session	Core concept	Therapeutic process
1	Introduction to ACT model and Living with Uncertainty	Creative hopelessness. The 'control agenda' and 'happiness trap'. Normalising the struggle.
2	Being present	Mindfulness. Self-as-context.
3	Opening up	Defusion. Expansion (acceptance). Urge surfing.
4	Doing what matters	Connection to values. Committed action. Moving forwards.

Underpinning each of the sessions is the emphasis on developing self-compassion and choosing workable actions (see Figure 2). This involves a novel shift away from struggling to control the uncontrollable and exploring what is under our control or influence. This can sometimes mean choosing an action that involves sitting with, rather than avoiding, difficult thoughts and feelings in the service of working towards an important value, i.e. being the person they want to be. An example that often arises is the desire to be a loving and caring parent or grandparent. Spending time with children and grandchildren can be joyous, but can also elicit painful fears about not being around as they grow up. The automatic reaction may be to avoid playing with them to avoid the pain, whereas the meaningful action may be to make space for the pain in

order to also experience the pleasure of sharing time with them. The importance of values related to self-care, compassion and savouring the present moment are most often realised during these poignant moments.

Figure 2: The ACT choice point model



Outcomes of the group

The core intended outcome of ACT is not symptom reduction, but instead an increase in quality of life, meaningful actions and psychological flexibility. Symptom reduction can sometimes occur as a by-product of the intervention but is not expected.

A small-scale preliminary analysis of this group programme as assessed by pre and post-scores for the Clinical Outcome in Routine Evaluation⁹ (CORE), ACT-based Acceptance and Action Questionnaire¹⁰ (AAQ) and the Functional Assessment of Cancer Therapy¹¹ (FACT) showed some interesting results. It was found that the group helped to improve participants' reported level of anxiety, depression, general and social functioning as measured by the CORE and their emotional well-being as measured by the FACT. With the relatively small number of measures completed so far, there was not a significant difference found in the level of psychological flexibility as measured by the AAQ. Verbal and

written evaluations of the group provided by participants highlighted how it can be challenging to confront difficult thoughts and feelings in the short-term, but that the longer-term benefits of having the opportunity to feel understood, have their feelings validated and develop additional coping skills were valuable.

Summary

Upon reflection of the use of this approach so far within an oncology setting, an important element seems to be the process of validating that there is no right or wrong way to think, feel or act when living with the impact of cancer. In addition, this approach enables people to, in their own way, develop their sense of control over the actions they take. For example, it may allow them to build their sense of fulfilment, savour small everyday moments and be kinder to themselves. It is this sense of control that appears to elicit an important shift in a

person's sense of resilience and ability to continue to live their life meaningfully in the moment, despite the cancer.

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Helping parents with cancer support their children

For many parents – plus carers, guardians, grandparents and other family members – one of the values they hold most strongly is the desire to keep their children safe from any harm, threat or distress.

Consider then what happens when an adult is faced not only with their own cancer diagnosis, but the thought about how they are going to continue to love and protect their children in the same way. Many parents are faced with difficult questions such as ‘How will I find the right words to tell them?’, ‘Who will look after them if I’m in hospital?’ and ‘What will happen to them if I die?’.

They may be less physically able to play with, support and care for their children in the way they wish. They may find themselves in a ‘cared for’ role rather than caring for their children as usual. This can be especially difficult in single parent families and families that have a very small support network nearby.

All this is added together with the inevitable disruption to the family’s usual routine caused by hospital appointments, treatment and admissions. Parents often describe feeling overwhelmed and at a loss to know what to do.

Children need to know that they will be loved, safe and cared for in order to maintain psychological resilience. Parental distress is likely to have an important impact on the parent’s confidence and ability to support their children and therefore also their children’s well-being. In general, children who have a parent with cancer are more likely to report higher levels of anxiety compared to the general population, with 6–12 year olds being more likely to experience greater internalisation and somatic symptoms. Parental anxiety has been found to account for the greatest variance in child adjustment.¹

Parents commonly worry that telling their children about the cancer would be too upsetting and try to protect them from distress by not telling them. However, this can unintentionally lead to their child feeling vulnerable and unable to talk openly with their family about their worries and fears.²

Only 50% of children are likely to be informed of parental cancer after diagnosis, with 19% still not knowing after their parent has undergone surgery or radiotherapy.³ In contrast, most children are likely to report that knowing about their parent’s diagnosis is helpful. Only 6% of 6–12 year olds and 11% of 13–20 year olds report that not talking or thinking about the parent’s illness helped.⁴

These findings are particularly important given that parents often underestimate the impact of their illness on their children. Children’s anxiety levels are specifically related to lack of knowledge about the illness.⁵ This highlights the importance of communication between parents and their children about the cancer and the need to support parents in doing this.

Common reactions to cancer in the family

Although younger children may have little understanding of illness, they are more aware of separation and disruption of routines. They may believe wishes can come true and a kiss will make everything better again. They may even believe that they made their parent ill by being naughty.

Some children may be afraid to show that they are frightened or lonely; they don't want to cry, or they want to be brave so they don't upset their parent. Young children may complain of frequent stomach aches, avoid being away from their parent or behave differently at home or school.



Older children can sometimes use friends more than family for support and comfort. This can sometimes appear as though they are indifferent. However, they may be at a stage in their lives where they are naturally moving towards their friendship groups and their own independence. They may appear resentful and angry if their time spent in out-of-school activities or with friends is compromised due to changes in family routines. Some teenagers may take any extra responsibility in their stride, while some may appear to grow up too quickly. For some, conflict may occur if their newfound responsibilities are taken away if their parent starts to feel better.

Parents may feel guilty and try to minimise the impact of the cancer on their family by not telling their children about it. Or perhaps by making promises they may not be able to keep, such as 'I promise I will get better'. However, they are often then faced with the dilemma of keeping secrets and the worry that their children could instead find out about the cancer from others, for example in the playground. Parents are often also keenly aware of how easily their children notice changes in the family, and how their children may come to the wrong conclusion about what is going on. With the parent already feeling overwhelmed, they may then find themselves feeling more impatient and irritable with their children as they struggle to cope with day-to-day life. Alternatively, they may try to compensate for the impact of the cancer by loosening their usual boundaries, saying 'no' less often or treating their children more, to try to alleviate their children's and their own distress.

Honesty and openness

Thinking about talking to children about cancer can understandably feel frightening. Parents may ask professionals to do it for them. However, supporting parents on

an emotional and practical level to have these conversations can help children feel safer, as they are told by someone they know, love and trust, rather than a stranger.

Letting parents know that they cannot protect their children from feeling sad, but that most children are able to cope with the information, can help them to begin to explore the longer-term outcomes of talking to their children about cancer. For example, this can help their children feel more supported and develop their resilience to difficult life events. Being honest and including their children in what's happening can give their children chances to ask questions and talk about their worries – helping them to feel less anxious and more supported. Using the word cancer and simple explanations can also help their children's understanding of what to expect and clear any misunderstandings that it isn't their fault and they cannot 'catch it' like a cold. For example: 'Daddy has a lump in his tummy and it's called cancer. The doctors and nurses are going to give some special cancer medicine to try to make daddy better.'

Explaining the treatment, side effects and planning for hospital visits can also help children to feel more prepared for changes and separation – to know that they are still loved even when their parent isn't with them. There is no 'right' time to tell children about cancer. Supporting parents to use creative resources such as books, toys and play exercises can help them find the words and help the family to explore their feelings about the cancer together. This can help make the painful conversations a little more manageable. Most importantly, it is alright to keep to usual routines and boundaries. Reminding parents that praise and having fun as a family are just as important now as ever can help the focus to be about the family, rather than the cancer.

Pre-bereavement work

Some parents may be facing the end of their lives and the prospect of leaving their children. Continuing to have open conversations about the cancer can help to prepare their children for this. When children and young people's support needs associated with bereavement and the accompanying changes are not identified, it can increase their risk of poor outcomes. For example, outcomes relating to education, self-esteem and risk-taking behaviour. This is particularly the case in disadvantaged socio-economic circumstances⁶, where outcomes can extend into adulthood.⁷

The death of a parent through cancer can result in quite different responses in children to those who have experienced unexpected bereavement.⁸ In particular, childhood bereavement models indicate that children may experience anticipatory stress or grief due to the awareness that the parent could or will die. Research into families where adults are facing the end of life through other illnesses, such as AIDS, has highlighted the positive impact of dying parents planning for their children. For example, by promoting relationships with the new carer and developing lasting important memories together.⁹ This research shows that even young children benefit from preparation and timely information, to help them to make sense of a very difficult situation and to receive support from the surviving parent or guardian. Resources such as memory boxes can help the parent to have these difficult conversations, as well as enabling the children to maintain their bond with their parent after their death.

Summary

Parents know their children better than anyone else. Deciding whether or not to tell their children about the cancer is a very difficult decision. Research shows the importance of supporting parents, not only to talk openly and honestly with their children, but also to continue caring for them throughout all stages of the illness. It appears that this could have a significant impact on the long-term adjustment of children and their ability to develop their resilience, strength and confidence in the face of adverse situation. Doing so could also help reduce parents' distress, and even strengthen family relationships.

Enabling parents to access this support from the point of diagnosis, and continuing to support them throughout their illness, appears particularly important. This seems to allow the highest chance of reducing long-term psychological difficulties for children and their families.

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Further information

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How a clinical psychologist can support shared decision-making

As a Macmillan clinical psychologist, part of my role involves supporting patients, their families and the breast care team in making decisions with regards to risk-reducing mastectomies (RRM).

There are two types of risk-reducing mastectomy: bilateral (BRRM) or contralateral (CRRM). A BRRM is the surgical removal of both breasts to help reduce the risk of developing breast cancer, which is carried out even though there is no evidence of cancer in the breasts. A CRRM is for women with a strong family history of breast cancer and/or who have cancer in one breast and decide to have the other breast removed to reduce the chance of getting breast cancer again. My experience to date has been working with patients considering having a CRRM. While the aim of the mastectomy is referred to as 'risk-reducing', in my experience (see case studies) and as indicated by evidence¹, patients' reasons for wanting an RRM are often multifaceted and go further than this.

The decision as to whether to have an mastectomy is a serious and significant one. It is a large operation which cannot be reversed, and like all surgery has its own risks. There are also additional considerations, such as whether to have a reconstruction or whether to wear prostheses. For this reason, it is important that the psychological implications of this procedure are considered. It's important that the patient's psychological suitability is assessed, and that the decision-making process of the patient, their family and the breast cancer team is supported.

The psychologist enables this by providing the patient with a safe and reflective space to explore their choices, thoughts, feelings, motivations and expectations, so they can make the best informed decision for their situation.² The psychologist typically

meets with the patient for an hour and a half for one to two sessions. The session is done jointly with a breast care nurse so that they can answer any medical questions about the procedure and recovery and also to clarify the patient's understanding about their risk of developing cancer or a recurrence. Prior to and at the beginning of the session, it is also important to provide information on the psychologist's role in the process.³ The patient is also sent the Macmillan guide *Understanding risk-reducing breast surgery*. Following the session, the psychologist provides written feedback (as discussed and agreed with the patient) to the referrer.

Case study one

Mrs P was referred by one of the breast surgeons. She said she was considering an RRM to reduce the risk of getting cancer in her other breast, and that she was mainly doing this for her daughter, because she did not want her to have to go through it again.

We explored Mrs P's decision thoroughly, looking at both the advantages and disadvantages of having the surgery. We concluded that it seemed this was not the best time for her to be making this decision, as she did not feel emotionally stable enough to do so – she needed more time to recover, process and come to terms with her cancer experience. Mrs P also said she felt she would not be able to cope with the emotional and psychological aftermath of having an RRM. We agreed it may be a good idea to give her time to see whether she could cope and live with the uncertainty of a cancer recurrence.

I suggested she could try attending our Living with Uncertainty group. We agreed the best outcome would be to ask for her RRM to be postponed, until she felt in a more emotionally stable place to make an informed decision. I wrote back to the breast surgeon making the recommendation. Following this, a decision was made by the surgeon and Mrs P to postpone the surgery for eight months. During this period Mrs P decided she did not want a RRM and cancelled the surgery.

Case study two

Mrs D was referred by one of the breast care nurses. Mrs D told me she was 100% sure and determined to have the surgery. Mrs D told me her main reason for wanting an RRM was to reduce the risk of her getting cancer again. Mrs D said she believed having an RRM would mean she could move forward with her life, as she would no longer have to worry about getting cancer in her other breast. She also said she wanted an RRM to restore symmetry.

Mrs D and I also talked about the disadvantages to having an RRM. She initially said she could not think of any. As we discussed this further, however, we outlined disadvantages, including the risks and complications of surgery, and the long recovery. She said she also realised that this will not stop cancer recurring elsewhere. I also highlighted that it is therefore unlikely to completely get rid of the fear of recurrence. However, Mrs D said she still felt that the advantages far outweighed the disadvantages. She was not concerned about further surgery. She said she coped with it previously and knew what to expect. She also said she would have plenty of support from her family and her workplace. She told me her previous mastectomy had not had a significant impact on her body image, feelings of femininity or sexuality. However, we talked about managing her expectations, as it may take time for her to adjust to having both breasts removed and the resulting change in appearance.

I wrote to the consultant, stating Mrs D's reasons for wanting a RRM seemed largely driven by her desire to reduce her feelings of vulnerability to a recurrence, and to regain trust and a sense of control in her body. Secondly, it seemed that she would like this surgery to achieve symmetry. I stated Mrs D appeared to have given this a lot of thought and was realistic in her expectations, and it seemed she would be able to cope psychologically with surgery and the recovery.

In summary, the decision as to whether to have a RRM is a serious and significant one for all involved in the process, including patients, families and professionals. It is important that patients are provided with a safe and reflective space to fully explore all elements of this decision, and to make informed choices. Clinical psychologists aid and support this process, and ensure patients' emotional and psychological well-being is kept central.

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Further information

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Psychological supervision for staff

Supporting cancer and palliative care staff to deliver psychological care through consultation, supervision, teaching and training is important.

A large and important part of the Macmillan clinical psychologist's role within cancer and palliative care services is to work alongside the multidisciplinary cancer and palliative care teams, to promote psychologically-informed care, and to support the psychological well-being of staff.

The NICE guidelines for improving supportive and palliative care for adults with cancer highlight this when it states that 'all staff providing psychological support within the recommended model will require training and ongoing supervision'.

The guidelines suggest that 'those working at the higher levels of the model should normally provide training, supervision and opportunities for continuing professional development for those operating at the lower levels' and that 'psychological specialists should also play a significant role in the development and maintenance of communication skills through teaching and training'.

Based on this, the psychologist's role aims to offer consultation, supervision, team formulation and reflective practice to all nurses and therapists in cancer and palliative care services.

Supervision at Cwm Taf UHB

At Cwm Taf University Health Board (UHB), supervision is delivered mainly on a group basis (with a maximum of 10–12 members of staff but typically 4–6 attend). However, occasionally it is delivered on an individual basis, either face-to-face or over the telephone. The consultation



sessions are delivered once a month for an hour and a half in a setting away from their immediate work space. The psychologist draws on a variety of psychologically-informed consultation/reflective practice models to do this. These models can include cognitive behavioural, systemic and solution-focused therapies.

Staff members are encouraged to set their own agenda for the sessions. The purpose of the session is to provide the staff with a safe reflective space to explore and discuss some of the following topics:

- A case of a patient experiencing psychological distress/difficulties.
- Space for reflective discussions of patient work.

- Discussion and reflection on a psychological difficulty that the consultee may be struggling with and/or want more knowledge on. For example, anxiety, low mood, risk, trauma or grief.
- Organisational issues.
- Discussions that may arise on any topic, but with a psychological focus.

The psychologist can also offer debrief sessions individually or as a group after a serious incident or event.

To ensure staff members feel comfortable and safe to reflect on their clinical practice, the sessions are kept confidential among those attending the session. The only time information would be shared was if the psychologist was concerned that harm may come to a staff member or the patients they are working with.

Another crucial part of the psychologist's role is to provide teaching and training to staff members to develop their level one and two psychological care. Below is a list of some of the teaching topics that have been provided. The majority of the teaching is delivered by the psychologist, but one of the teaching topics has been provided by an external facilitator using the Macmillan Group Learning and Development Grant:

- Psychological impact of cancer.
- Assessing risk (e.g. suicide and self-harm).
- The psychological impact of cancer on relationships/couple/families.
- Self-care for staff.
- Breaking bad news.
- Anxiety and cancer.
- Cancer-related fatigue.
- Loss and grief models
- Introduction to cognitive behavioural therapy concepts.
- Brief solution-focused therapy (external facilitator).

Feedback from staff

Staff members have provided the following feedback on the consultation and on the teaching sessions:

'This has been a forum for education and, peer support, and has been extremely beneficial to our practice.'

'As a lone specialist nurse, I have found great benefit in the regular meetings for CNSs. They have provided me with education, as well as a forum for peer discussion on difficult cases/situations. The two-day session on solution-focused therapy was invaluable and really does work when used with patients. Between meetings, having the opportunity to discuss patients/situations with the clinical psychologist over the telephone has been very helpful and I feel that this has actually taken some stress out of the job.'

'Since attending the psychology workshops, I have felt more reassured that I am giving the right support and that I am acknowledging their distress, saying the right things and listening to patients ... I am much more able to identify those that may need specialist psychological support. Therefore, the psychology workshops have been a valuable resource to me and the team.'

'As well as a valuable learning resource, the workshops have enabled us (i.e. specialist nurses) to discuss difficult situations that we have encountered in our work, and then as a group, discuss how we could have best handled the situation. We have learned from each others' experience.'

Further information

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Extend your psychological support skills

If you would like to extend your skills in supporting patients psychologically and emotionally, there are a number of routes to explore.

Macmillan training courses

Macmillan runs a rolling programme of training events. Examples of recent courses include:

- mindfulness
- advanced communication skills
- breaking bad news
- emotional well-being
- motivational interviewing
- supporting and working with bereaved children.

Visit learnzone.org.uk or contact your local Macmillan Learning and Development Manager.

Macmillan training grants

Macmillan training grants are available for individuals or groups.

The grant could be used to set up a local training event. For example, within South Wales, psychologists have used this grant to set up a two-day workshop presented by an expert in the area of solution-focused practice. Participants from a range of disciplines rated this as extremely useful for their own clinical practice. Similar workshops with an external trainer could be set up in topics such as brief cognitive behavioural therapy (CBT) or solution-focused practice. Or you could organise a local training workshop for your team and other relevant attendees, for example clinical nurse specialists and allied health professionals. With Macmillan's approval, such group training can be open to non-Macmillan professionals.

Your area may have a local clinical psychologist who could deliver such training or help with identifying skilled external trainers.

Visit grants.learnzone.org.uk or contact your local Macmillan Learning and Development Manager.

Consultation/supervision

Approach your local clinical psychologist to discuss whether they may be available to offer clinical consultation or supervision either singly or to a group or team of professionals.

Suggested reading

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