Background to the

Cancer Psychology Referral Guidelines

Robin Paijmans
Macmillan Clinical Psychologist
Summary

Cancer is a series of traumatic stresses and events. Cancer patients and their families face multiple challenges in the areas of resuming and maintaining life activities, coping with treatment and side-effects, managing the emotional impact and stresses and adjusting to significant long-term losses and changes. The complexity and severity of these challenges reflects the complexity and severity of the cancer, its treatment and the patient’s personal life circumstances and challenges before cancer. As such some challenges can be adequately addressed by listening to and acknowledging the concerns or by the provision of information, way-pointing to cancer support services, basic problem solving or other straightforward interventions that lie within the remit and expertise of most health care professionals (level 1 and 2 of the NICE Guidance on Psychological Support in Cancer Care). Other challenges however are of such a complexity or generate such psychological distress and disorganisation that they require a specialist expertise in psychological assessment and intervention (level 3 and 4 of the NICE Guidance on Psychological Support in Cancer Care).

It is appropriate to make a referral to the Cancer Psychology Services when the cancer patient or family are significantly distressed (i.e. to the extent that engagement in treatment, maintenance or resumption of activities of daily living or important relationships are threatened) and this cannot be sufficiently addressed by Level 1 or Level 2 intervention.

To make a referral in Birmingham the referral form in appendix 1 should be used. It can be downloaded from the Pan-Birmingham Cancer Network website http://www.birminghamcancer.nhs.uk/ or be requested from the Cancer Psychology Service directly by e-mail cancer.psychology@uhb.nhs.uk or telephone 0121 - 627 5758. It can be sent as an e-mail attachment to: cancer.psychology@uhb.nhs.uk or printed and posted to: Cancer Psychology Service, Cancer Centre, University Hospital Birmingham B15 2TH.

To make a referral in Walsall the referral form in appendix 2 should be used. A copy of this form can be requested from the Wallsall Community Health Psychology Services directly by telephone 01922 - 858 450 and sent as an e-mail attachment to: tracy.russell@dwmh.nhs.uk. Alternatively it can be printed and posted to: Psychology Services (Walsall Community Health), Greybury House, Bridge Street, Walsall, WS1 1EP or faxed to Fax Number: 01922 - 858 453.

For support with patients whose psychological distress warrants intervention at Level 1 or Level 2, or for those patients who refuse a referral to the Cancer Psychology Services, the health professional can contact the service for advice and support. The Cancer Psychology Services supports health care professionals by co-working and by offering advice, training, supervision, case discussion and consultation either 1:1 or in peer group meetings, workshops and presentations.
Introduction

Psychology is the *science of human behaviour* -- what makes people think and feel and behave the way they think and feel and behave. Clinical psychology concerns itself with how the way that somebody thinks and feels and behaves can cause them serious problems in their daily life functioning and actualisation of their life goals. Clinical Psychologists do not only work with people who have mental health problems; they also specialise in helping people cope with extraordinary circumstances. In the field of cancer care, clinical psychologists specialise in helping people cope with and adjust to the emotional trauma and stresses that can accompany a serious physical illness like cancer.

The diagnosis of Cancer can be regarded as a traumatic event which can challenge the patient’s most fundamental beliefs about life, themselves, and their future, and which may leave them feeling overwhelmed and powerless. The cancer journey is a series of stresses: the patient is faced with making many decisions about cancer treatment for which complex information about surgery, chemotherapy or radiotherapy must be understood and their relative benefits and drawbacks considered. Cancer treatment itself is an unfamiliar and sometimes frightening experience with many uncomfortable (and possibly quite serious) side-effects. After cancer treatment additional challenges may be faced in terms of resuming daily life, personal intimacy, and occupational functioning while adjusting to losses or changes in body functioning or appearance and facing a future less certain. When cancer treatment cannot achieve remission, drastic psychological adjustment may be required in coming to terms with reduced or declining function and a foreshortened future.

As such, cancer patients and their families face multiple challenges in the areas of resuming and maintaining activity and independence, coping with treatment side effects, accepting cancer and maintaining a positive outlook, seeking and understanding medical information, regulating feelings associated with cancer experiences, seeking support and managing stress and adjusting to significant loss and change.

These challenges do not always present themselves to the same extent and complexity in all patients and their families. Some can be adequately addressed merely by listening to and acknowledging the concerns; others can be dealt with by the provision of information, way-pointing to cancer support services, basic problem solving or other straightforward interventions that lie within the remit and expertise of most health care professionals working at Level 2 of the NICE guidelines on Psychological Support in Cancer Care (see fig. 1).
More complex challenges may arise when:

- the patient feels unable to prepare for treatment because (s)he does not get enough information or does not understand it;
- the patient does not feel able to establish a relationship of trust with the professionals who treat them;
- the patient or family already has (had) other serious problems and stresses in their life that make significant demands on their coping resources;
- the patient does not have support from family or friends during the cancer journey;
- problems in maintaining daily life functioning (e.g. work, finances, shopping, household tasks, looking after the children) are not addressed.

Other risk factors for a more complicated presentation of adjustment difficulties are:

*In the patient/family:*

- A history of psychiatric disorder
- Social isolation
- Dissatisfaction with past medical care
- Passive coping (i.e. not seeking information/ not talking to friends/family)

*In the cancer:*

- Limitation of daily life activities
- Disfigurement
- Poor prognosis/survival

*In the treatment:*

- Disfigurement
- Isolation (such as in e.g. bone marrow transplant or thyroid radiation therapy)
- Debilitating or distressing side effects
- Post Traumatic Stress Disorder
These factors may interact with multiple problems in the aforementioned network of challenges to require an expertise in psychological assessment and intervention as outlined in Level 3 and Level 4 of the NICE Guidelines. In such cases, a referral to the Cancer Psychology services is warranted.

<table>
<thead>
<tr>
<th>Level</th>
<th>Group</th>
<th>Assessment</th>
<th>Intervention</th>
</tr>
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<tbody>
<tr>
<td>1</td>
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<td>Recognition of Psychological Needs</td>
<td>Effective information giving, compassionate Communication and General Psychological Support</td>
</tr>
<tr>
<td>2</td>
<td>Health and Social Care Professionals with additional experience</td>
<td>Screening of Psychological Distress</td>
<td>Psychological techniques such as Problem Solving</td>
</tr>
<tr>
<td>3</td>
<td>Trained and accredited Professionals</td>
<td>Assessment of Psychological Distress and Diagnosis of some Psychopathology</td>
<td>Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework</td>
</tr>
<tr>
<td>4</td>
<td>Mental Health Specialists</td>
<td>Diagnosis of Psychopathology</td>
<td>Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)</td>
</tr>
</tbody>
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*Fig 1: The NICE Guidance Four-level model*
The role and remit of the Cancer Psychology Service

The Cancer Psychology Service provides assessment, intervention and support for patients/families who are struggling to cope with e.g.:

1. Understanding, engaging in, and coping with cancer treatment
2. Pain, discomfort, fatigue and other side-effects;
3. Feelings of depression, hopelessness, anxiety and anger;
4. Managing the demands of home, working and family life while caring for themselves;
5. Adjustment to loss and change in physical functioning;
6. Adjustment to loss and change in physical appearance;
7. Adjustment to loss and change in self-esteem and sense of self;
8. Adjustment to loss and change in sexual functioning and intimacy;
9. How cancer affects personal and social relationships;
10. Adjustment to loss and change in life roles and aspirations;
11. A sense of uncertainty about the future and life expectancy.

The above list should not be regarded as an exhaustive or mutually exclusive list of adjustment difficulties that cancer patients and their families may encounter. Rather, it is more reflective of reality to view the above challenges as a network of interconnected and overlapping domains against a backdrop of people’s cultural, spiritual, practical and socio-economic circumstances (fig. 2). However for practical purposes in these guidelines the challenges will be discussed in a linear order.
**Fig 2: Some of the main challenges for people coping with cancer**
1. Understanding, engaging in, and coping with cancer treatment

Difficulties in this area may manifest themselves as:

- Difficulty engaging in or adhering to treatment to the extent that treatment is compromised (avoidance behaviour, extreme distress);
- Inability to consent or not consent to treatment on the basis of valid and informed decision making, by reason of diminished mental capacity or incapacitating distress;
- Cognitive and emotional difficulty in understanding complex information and decision making;
- Specific phobias, such as blood/injury phobia or needle phobia;
- Reliving of specific traumatic events e.g. previous serious illness or injury, or of personally intrusive experiences such as physical, sexual and/or emotional abuse.

Interventions may involve an assessment of capacity, assessment of the patient/family’s understanding and interpretation of the disease and its treatment; assisting in explaining and clarifying questions about treatment and exploration and containment of distress through management and treatment of phobias, anxiety, depression and/or PTSD symptoms.

2. Pain, discomfort, fatigue and other side-effects

Difficulties in this area may manifest themselves as:

- Long-term pain, discomfort, nausea and/or fatigue severe enough to disrupt activities of daily living, engagement in treatment, appetite (to the extent of causing significant weight loss) and/or sleep;
- Anticipatory nausea and vomiting and/or an increased experience of pain and discomfort as a conditioned response to the treatment experience;
- Insufficient internal or external coping resources to contain such symptoms, leading to maladaptive coping behaviour (e.g. addictive behaviours, avoidance of treatment or essential activities of daily living, withdrawal and social isolation);
- Loss of confidence and mood disorders (generalised anxiety, depression, decompensation, suicidal ideation).

Interventions generally involve an assessment of symptoms and their psychological and behavioural correlates, symptom management strategies such as relaxation, distraction, graded exposure/systematic desensitisation, pacing, exercise regimes; and may involve rehabilitative management and modification of their psychological and behavioural triggers and consequences. Interdisciplinary working with disciplines such as Chemotherapy staff, CNSs, Physiotherapists, Occupational Therapists and Pain Management or Palliative Care teams may be required.
3. Feelings of depression, hopelessness, anxiety and anger

Difficulties in this area may manifest themselves as:

- Overwhelming feelings of anxiety, despair, anger, or flatness of affect that last longer than a few weeks and disrupt the ability to maintain activities of daily living or self care, engaging in or coping with treatment or coping with side-effects, impair normal sleep or appetite;

- Very negative perceptions of self, life and future, such as self-loathing or low self-esteem, loss of interest/motivation, catastrophic thinking and fatalism (‘giving up’), hopelessness, or an inability to perceive a worthwhile life or future;

- Suicidal ideation or behaviour, risk-taking, addictive or other self-harming behaviour.

Immediate interventions generally involve an assessment of symptoms and their psychological and behavioural correlates, symptom management strategies such as relaxation, distraction and pleasant event scheduling; eliciting and exploring fears and worries and where appropriate challenging distorted negative perceptions, developing coping strategies to address specific concerns, providing appropriate cathartic outlets for anger. Suicide risk assessment may take place and referral to appropriate mental health agencies made for additional support. Longer term interventions may focus on issues of personality, self-perceptions and self-worth, significant life roles and goals, sources of personal validation and previous significant losses or changes. Cancer Support charities offer access to complementary therapies which may be useful for managing symptoms of anxiety.

4. Managing the demands of home, working and family life while caring for themselves

Difficulties in this area may manifest themselves as:

- Difficulty in maintaining essential activities of daily living such as personal care, preparing meals, managing household activities, child care or work, leading to self-neglect, significant neglect of the household environment, inability to meet the emotional or care needs of the children, sick leave from, or having to give up work;

- An associated experience of stress and feeling overwhelmed and feelings of guilt, shame and inadequacy, anger, loss of confidence, anxiety and depression.

Interventions generally involve an assessment of mood, stress and their physiological, psychological and behavioural correlates, an opportunity for catharsis and expressing and exploring concerns and perceived demands, stress management strategies such as relaxation, distraction and re-examining and re-prioritising perceived demands, assessing available resources, problem solving, forward planning and pacing strategies; and may involve referral to Cancer Information and Support services, the Macmillan Benefits Team at the Citizens Advice Bureau and social services. In rare cases decisions may have to be made about child welfare and safety.
5. **Adjustment to loss and change in physical functioning**

   Difficulties in this area may manifest themselves as:

   - Significant emotional difficulty in accepting losses and changes in physical functioning or in accepting the need to acquire new skills, behaviours and/or prostheses to compensate for loss or change in physical functioning;
   - Difficulty in maintaining or resuming activities of daily living and/or rigid attempts at maintaining old habits and ways of performing them even though they do not work anymore;
   - Loss of intimacy and sexuality;
   - Loss of confidence and self-esteem, withdrawal and/or social isolation;
   - An experience of feeling overwhelmed and feelings of self-loathing, shame and/or inadequacy, anger, anxiety and depression.

   Interventions generally involve an assessment of mood, coping adjustment behaviours, the grieving process and the personal meaning of the loss or change in physical functioning to the patient (and possibly the spouse and family). This may be against a backdrop of an assessment of their personality, significant life roles and previous significant losses or changes. Interventions are aimed at facilitating the adjustment and grieving process. Interdisciplinary working with disciplines such as CNSs, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Sexual Therapists or Palliative Care teams may be required.

6. **Adjustment to loss and change in physical appearance**

   Difficulties in this area may manifest themselves as:

   - Significant emotional difficulty in accepting physical scarring, cosmetic prostheses or cosmetic results of reconstructive surgery aimed at restoring physical appearance;
   - Loss of intimacy and sexuality;
   - Loss of confidence and self-esteem, withdrawal and/or social isolation;
   - Preoccupation with perceived physical defects, feelings of self-loathing, shame and/or inadequacy, anger, loss of confidence, anxiety and depression;
   - Neglect of personal care; loss of appetite with associated weight loss or overeating and weight gain.

   Interventions generally involve an assessment of mood, coping and adjustment behaviours, the grieving process and the personal meaning of the loss or change in physical appearance to the patient (and possibly the spouse and family). This may include an exploration of their personality, self-perceptions and self-worth, significant life roles and goals, sources of
personal validation and previous significant losses or changes. Interventions are aimed at facilitating the adjustment and grieving process. Interdisciplinary working with disciplines such as CNSs, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Sexual Therapists or Palliative Care teams may be required.

7. Adjustment to loss and change in self-esteem and sense of self

Difficulties in this area may manifest themselves as:

- Loss of confidence and ability to cope with activities of daily living, withdrawal and/or social isolation, possibly accompanied by increased anxiety and phobic avoidance;
- An experience of feeling overwhelmed and feelings of guilt, shame and/or inadequacy, anger, anxiety and depression;
- Loss of intimacy and sexuality;
- Neglect of personal care; loss of appetite with associated weight loss or overeating and weight gain.

Interventions generally involve an assessment of mood, coping and adjustment behaviours and the personal meaning of cancer-related losses and changes to the patient (and possibly the spouse and family). This may include an assessment of their personality, self-perceptions and self-worth, significant life roles and goals, sources of personal validation and previous significant losses or threats to these and associated coping behaviour. Intervention may involve CBT, Transactional Analysis, Personal Construct Psychology, CAT or more psychodynamic modes of therapy.

8. Adjustment to loss and change in sexual functioning and intimacy

Difficulties in this area may manifest themselves as:

- Significant difficulties in maintaining or resuming a sense of closeness and intimacy with partner;
- Loss of desire or emotional/physical energy for sex;
- Physical impairment or disability interfering with sexual activity;
- Erectile dysfunction, vaginismus, pain or other discomfort during sexual intercourse;
- Difficulty achieving orgasm;
- Loss of self-esteem, body image/awareness, sensuality or sexuality.

Interventions generally are couple-focused although a patient does not have to be in an active sexual relationship to be seen. They may involve an assessment of mood, coping and adjustment behaviours, the grieving process and the personal meaning of the loss or change in physical appearance and functioning to the patient (and possibly the spouse). This may
include an assessment of significant attachment relationships and previous sexual experiences. Aims are to help the couple establish and increase feelings of sensuality and intimacy and where necessary finding new ways of expressing themselves sexually following physical disablement. Joint working with Sex Therapists may be required.

9. How cancer affects personal and social relationships

Difficulties in this area may manifest themselves as:

- Significant difficulties in maintaining or resuming a sense of closeness and intimacy with partner;
- Significant difficulty in maintaining or resuming life roles within the family, as partner, parent/carer and/or breadwinner;
- Social isolation through withdrawal by social support networks being unable to cope or stigmatising the patient;
- Personal withdrawal from social support networks because of shame/stigma, loss of self-esteem and/or confidence, depression, fatigue, impairment in mobility or communication ability.

Interventions may involve the partner and family and may involve an assessment of mood, coping and adjustment behaviours and the personal meaning of the cancer-related losses and changes to the patient, spouse and family, their social support network and possibly their socio-cultural background. Intervention may involve CBT, Transactional Analysis, Personal Construct Psychology or Systemic and Behavioural Family Therapy approaches. Where practical or disability issues affect the ability to maintain relationships, interdisciplinary working with disciplines such as CNS’s, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Palliative Care teams and Cancer Support charities may be required.

10. Adjustment to loss and change in life roles and aspirations;

Difficulties in this area may manifest themselves as:

- Very negative perceptions of self, life and future, such as self-loathing or low self-esteem, loss of interest/motivation, catastrophic thinking and fatalism (‘giving up’), hopelessness or an inability to perceive a worthwhile life or future;
- Significant emotional difficulty in accepting losses/changes in ability and roles and in exploring and acquire new skills or roles;
- Rigid attempts at maintaining previous life roles or aspirations even though they may have become unattainable or unrealistic and resistance to exploring new roles, activities or aspirations;
It should be noted that an initial sense of hope and longing for, and striving to regain their pre-morbid life is not maladaptive but a natural response that may help to keep the patient motivated and focused in getting through the challenges of cancer diagnosis and treatment. Only when such feelings start to interfere with more adaptive responses to a changed life after cancer should they be regarded as a problem.

Interventions generally involve an assessment of mood, coping and adjustment behaviours and the personal meaning of cancer-related losses and changes to the patient (and possibly the spouse and family). This may include an assessment of their personality, self-perceptions and self-worth, significant life roles and goals, sources of personal validation and previous significant losses or threats to these and associated coping behaviour. Intervention may involve CBT, Transactional Analysis, Personal Construct Psychology, Schema-Focussed therapy or more psychodynamic modes of therapy.

11. A sense of uncertainty about the future and life expectancy.

Difficulties in this area may manifest themselves as:

- A sense of ‘hyper-arousal’: generalised anxiety, panic attacks and an exaggerated sense of vulnerability, irritability, disturbed sleep and fatigue;
- Nightmares about death, illness, harm and loss, nightmares, flashbacks or ‘reliving’ the cancer diagnosis, treatment and associated traumatic experiences;
- Intrusive thoughts/worries about death, illness, harm and loss;
- Hypervigilance of body symptoms and sensations and/or possible (health) threats to self or family;
- An impending sense of doom, foreboding or loss and pre-occupation with a negative or foreshortened future;
- Fundamental change in attitude towards important personal and life issues such as personal safety, life ambitions, religion and personal values, often characterised by a sense of disengagement, indifference, loss of motivation and hopelessness;
- Very negative expectations about future, catastrophic thinking and fatalism (‘giving up’);
- An inability to move on from grieving, re-invest in life and start looking ahead and planning for the future.

Immediate interventions generally involve an assessment of symptoms and their psychological and behavioural correlates, symptom management strategies such as relaxation, distraction, thought stopping and other forms of cognitive containment; eliciting and exploring fears and worries and where appropriate challenging distorted negative perceptions and understanding of risk, developing coping strategies to address specific concerns, providing appropriate cathartic outlets and rituals for working through grief. Suicide risk assessment may take place and referral to appropriate mental health agencies
made for additional support. Longer-term interventions may address the patient’s (and possibly the spouse and family’s) personal life beliefs of about meaning, predictability and controllability and may involve CBT, Transactional Analysis, Personal Construct Psychology, Schema-Focussed therapy or more psychodynamic modes of therapy.

The Referral Process

In making a referral to the cancer psychology service it is important that the health professional understands the role and remit of cancer psychology so that referrals can be made appropriately, and so the person who is offered a referral can be explained clearly and adequately what is being offered to them. A referral to a cancer psychologist should be presented like a referral to any other health professional. It offers an opportunity to talk with someone trained in emotional well being about their cancer concerns in a confidential setting, and offers the opportunity to explore different, more effective ways of coping with the problems and concerns associated with having cancer.

It is appropriate to make a referral when the patient or family are significantly distressed (i.e. to the extent that engagement in treatment, maintenance or resumption of activities of daily living or important relationships are threatened) and this cannot be sufficiently addressed by:

- Clinical Nurse Specialist
- Complementary Therapist
- Chaplaincy
- Cancer Support Services
- Pain Management Team
- Palliative Care Team (if appropriate)

Aspects of the distress that need to be considered are:

- severity of the emotions
- duration of the distress
- complexity of the issues
- meaningfulness of the distress to the patient
- resources available to the individual
- The wish of the patient to have a psychological intervention

Although a referral can be made at any time, a holistic screen such as the Patient Concerns Checklist (Appendix 1) performed at key points in the cancer care pathway may provide a particularly useful framework for a discussion with the patient about problems that may warrant a referral and the patient’s amenability to such a referral (see fig. 3).

**What if the patient turns down a referral?**

The foundation of a successful and lasting psychological intervention is the therapeutic relationship, which is impossible to establish if the patient does not want to see a psychologist. However there are rare occasions in which the refusal of a referral to a psychologist by the patient, their spouse or family is a manifestation of their adjustment and coping problems (e.g. extreme denial or avoidance) which warrant the referral in the first place. In that case it is recommended that the referring professional contacts the Cancer Psychology Service so they can discuss how the patient or family could possibly be persuaded to meet with the psychologist on a ‘no obligation’ introductory basis, or to advise and support the health professional in delivering some psychologically supportive interventions that are acceptable to the patient, spouse and family and that lie within the range of the health professional’s skills and remit.
Fig 3: The referral pathway for cancer psychology

- Does the patient/family experience psychological problems/distress (see fig. 1)?
- Does this interfere with cancer treatment, coping, daily life activities, important relationships?

Step 1: Help the patient identify their feelings and how tolerable or manageable they are at the moment:
- “How are you feeling exactly?”
- “How long have you been feeling that way?”
- “What helps you cope?”
- “What might help right now?”
- “Is there anyone (friends/family/cancer support services) that you can call on for support?”

Step 2: If this does not address the patient’s distress then offer support from e.g.:
- Clinical Nurse Specialist
- Complementary Therapist
- Chaplaincy
- Cancer Support Services
- Pain Management Team
- Palliative Care Team (if appropriate)

Step 3: If the patient continues to be distressed or their needs cannot be met by these services:
- Ask them whether they would like to see a member of the Cancer Psychology Service
- Make referral to Cancer Psychology Service

Step 4: Select appropriate Cancer Psychology referral form (Birmingham or Walsall)

Step 5: Complete form and save; send as attachment or print and fax or send by post

Step 6: Out-patient/family will be offered an appointment within one week and seen within 31 days; In-patient will be seen within two working days
Services for Health Professionals

The Cancer Psychology Services supports health care professionals by co-working and by offering advice, training, case discussion and consultation either 1:1 or in peer group meetings, workshops and presentations.
Example of the 4 levels in practice

Mrs Smith, 42, is married and the mother of two children (a boy, 12 and a girl, 15). She has been diagnosed with breast cancer which is being treated with a lumpectomy, chemotherapy and radiotherapy.

<table>
<thead>
<tr>
<th>Level</th>
<th>Presentation of Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Her prognosis is hopeful but still uncertain. She is approaching the end of her chemotherapy and has been off work for six months. She is fatigued, describes herself as a bit flat and listless. She finds herself thinking about her cancer a lot and feels unusually irritable with her husband and children.</td>
</tr>
<tr>
<td>2</td>
<td>In addition to the above, Mrs Smith feels she often does not want to see people. She frequently expresses worry about the future and about bodily symptoms, which is aggravated by uncomfortable side-effects from chemo- and radiotherapy. There are times when she can enjoy herself but often she feels a bit anxious and low in mood. On the whole, however, she feels that she is coping.</td>
</tr>
<tr>
<td>3</td>
<td>Mrs Smith has been feeling low for several months. She feels tired and achy, overwhelmed with household tasks and worries that she is not able to be a good mother and that she has become a burden on her family. She is convinced that the cancer will return. She feels that she has lost the person she used to be, feels disfigured and unattractive and that she is drifting apart from her husband. He appears unable to talk about her fears and has stopped touching her. She has begun dreading a return to work and has lost confidence; she had her first panic attack going out last week.</td>
</tr>
<tr>
<td>4</td>
<td>Mrs Smith feels hopeless and depressed and has thoughts of ‘just ending it all’. This frightens her as it reminds her of the nervous breakdown she had five years ago when her mother died of breast cancer. She is convinced that her daughter will ‘inherit’ breast cancer too and feels devastatingly guilty about this. Meanwhile biopsy showed tumour spread and eventually she had to have a mastectomy; now she feels ‘an ugly freak’, and this evokes feelings about when she had anorexia nervosa as a teenager. Her husband is frustrated with her withdrawal and, feeling angry and helpless, has started spending a lot of time at the pub. His work is suffering and that increases her fears about finances. Their daughter seems more withdrawn and their son has been getting into trouble at school a lot.</td>
</tr>
</tbody>
</table>
This table is not meant to show the development of a single case over time, but to illustrate four separate hypothetical cases of increasing complexity. The same personal details and diagnosis have only been used for clarity of comparison. Similarly, referrals do not have to ‘work up’ through the levels; i.e. a professional working at L1 or L2 can directly refer to an L4 professional if the complexity of the case warrants it.

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Appendix

- Example of a Holistic Needs Assessment: the Wellbeing Assessment
- Cancer Psychology Referral Forms:
  - Birmingham
  - Walsall
- Cancer Psychology information leaflet for patients
### Patient Details:

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
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<tbody>
<tr>
<td>Surname</td>
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<table>
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<td>Date of referral</td>
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<td>Cancer site</td>
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<td>Current status</td>
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<td>Diagnosis</td>
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<tr>
<td>Reasons for referral</td>
<td></td>
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</tbody>
</table>

Patient knows about referral and agrees to it? □ Yes □ No

Any other details that would be helpful for us to know?
Cancer Psychology Service - Referral Route & Criteria

Referral Route:

This service is available for patients, their families and carers. Referrals can be made by all cancer and palliative care nurses, doctors and surgeons. Referrals need to be made with this form. Fill it out on screen and then save the result to your computer. Then send the form you just saved as an e-mail attachment to:

cancer.psychology@uhb.nhs.uk

Alternatively, the saved form can also be printed out and sent by post or fax to:

Ms Karen Bassett
Cancer Psychology Service Secretary
Cancer Centre, Queen Elizabeth Hospital
University Hospital Birmingham, B15 2TH

For any queries please call: 0121 - 627 5758 (or inside Queen Elizabeth Hospital xt. 6358)

If you are unsure whether a referral to psychology is appropriate, please contact your local cancer psychologist by telephone or e-mail. If you are unsure how/where, please contact the cancer psychology secretary and she can tell you who covers your hospital.

Referral Criteria:

This service is funded to provide a specialist level of support in helping people (both patients and partners/relatives) cope with cancer, its treatment and its consequences. Some examples of the issues we work with are:

- coping with a sense that the future is uncertain;
- coping with how cancer affects relationships;
- managing the demands of home and family life while caring for oneself;
- feelings of depression, anxiety and anger;
- coping with disfigurement and disability;
- coping with adjustment, change, loss;
- coping with pain, discomfort, fatigue and treatment side-effects;
- coping with how cancer affects sexual functioning;
- coping with how cancer affects self-esteem and sense of self.

It is important that the patient agrees to being referred to a psychologist. Patients will generally be offered appointments at the Hospital, although some adjustments can be made if they are medically unfit to travel. The Cancer Psychology Service cannot offer an emergency service. In case of an emergency mental health referral, please contact liaison psychiatry.

Other Services:

In addition to helping patients, families and carers, we support health care professionals by co-working and by offering advice, training, case discussion and consultation either 1:1 or in peer group meetings, workshops and presentations.
# Cancer Psychology Services Referral Form

## Referral Date:

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<thead>
<tr>
<th>Priority:</th>
<th>Urgent (within 7 days)</th>
<th>Moderate (within 2 weeks)</th>
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<td>□ Mild (within 1 month)</td>
<td>□ Low (within 1 – 2 months)</td>
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<td>Appointment Type:</td>
<td>□ Home Visit</td>
<td>□ Out Patient/Clinic</td>
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<td>(Home Visits are for patients with mobility issues or terminal diagnosis)</td>
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## Patient Details:

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<th>Forename:</th>
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## Referrer Details:

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<th>Date of referral:</th>
<th>Referred by:</th>
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<td>Referrer Profession:</td>
<td>Specialty:</td>
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<td>Referrer address:</td>
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## Referral Details:

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<th>Cancer site:</th>
<th>Current status:</th>
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<tr>
<td>Diagnosis:</td>
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<td>Reasons for referral?</td>
<td>Patient knows about referral and agrees to it? □ Yes □ No</td>
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<tr>
<td>What are the patient’s psychological difficulties?</td>
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Any other details that would be helpful for us to know? (including mobility status/other health professionals and services involved) or any issues of risk)
Cancer Psychology Service - Referral Route & Criteria

Referral Route:

This service is available for patients, their families and carers. Referrals can be made by all cancer and palliative care nurses, doctors and surgeons. Referrals need to be made with this form which can be sent by post, faxed or e-mailed as an attachment (more referral forms are available from the Cancer Psychology Department). Please send referrals as follows:

For Community Home Visits/Hospice to:  
Dr Helen Guy  
Macmillan Clinical Psychologist

For Out Patients/In Patients to:  
Dr Shradha Lakhani  
Lead Clinical Psychologist  
Palliative Care/Oncology

Psychology Services (Walsall Community Health)  
Greybury House, Bridge Street, Walsall, WS1 1EP

Telephone: 01922 - 858 450  
Fax: 01922 - 858 453  
e-mail: tracy.russell@dwmh.nhs.uk

For any queries please call: 01922 - 858 450 and ask for Barbara or Tracy (secretaries).

If you are unsure whether a referral to psychology is appropriate, please contact your local cancer psychologist by telephone or email. If you are unsure how/where, please contact the cancer psychology secretaries and they can tell you who covers your area.

Referral Criteria:

This service is funded to work with people (both patients and partners/relatives) struggling to cope with cancer, or issues arising as a result of their cancer, where the health professionals involved feel it is necessary to provide a specialist level of support. Some examples of the issues we work with are:

- coping with a sense that your future is uncertain;
- coping with how cancer affects your relationships;
- managing the demands of home and family life while caring for yourself;
- feelings of depression, anxiety and anger;
- coping with adjustment, change and loss;
- coping with pain, discomfort, fatigue and treatment side-effects;
- coping with how cancer affects your sexual functioning;
- coping with how cancer affects self-esteem and sense of self.

It is important that the patient agrees to being referred to a psychologist. Patients can be offered out patient appointments, in patient appointments or home visits but only if the patient is unable to travel due to ill health. The Cancer Psychology Service cannot offer an emergency crisis service. In case of an emergency mental health referral please contact: Dorothy Pattison Hospital (out of working hours) on: 01922 - 858 000.

Other Services:
In addition to helping patients, families and carers, we support staff by co-working and by offering advice, training, case discussion, supervision and consultation either one to one or in peer group meetings, workshops and presentations.
What is this leaflet about?

Your doctor, nurse or other health care professional who knows you well, may suggest you talk to a cancer psychologist. Cancer affects the whole person, not just the body, and they know you may benefit from talking about the emotional effects of your illness. Cancer also affects the family, so even if it is not you who has cancer but someone close to you, you may still feel affected and could benefit from talking to someone in confidence.

This leaflet explains what a cancer psychologist is, what difficulties they can help you with, and how you can be referred to this service.

What do psychologists do?

Psychology is the science of human behaviour: what makes people think and feel and behave the way they think and feel and behave.

Clinical Psychology is concerned with how the way that somebody thinks and feels and behaves may cause them serious problems in their daily life functioning. It is a common belief that Clinical Psychologists only work with people who have mental health problems, but this is not the case. They also specialise in helping people cope with extraordinary circumstances.
Cancer psychologists specialise in helping people cope with and adjust to the emotional stresses and strains that can accompany serious physical illness. It is the situation that is abnormal, NOT the person or their reaction.

What is the role of psychologists working with cancer patients?

You may have talked to a number of health care professionals, family members and friends about your illness and its impact, your worries and concerns, your feelings, how you try to manage carrying on with your daily life or about how treatment affects you. You can talk to a psychologist about these issues also, in a confidential setting. The sorts of difficulties they can help you with include:

- coping with a sense that your future is uncertain;
- coping with how cancer affects your relationships;
- managing the demands of home and family life while caring for yourself;
- feelings of depression, anxiety and anger;
- feeling unhappy about the way you look;
- coping with adjustment, change and loss;
- coping with pain, discomfort, fatigue and treatment side-effects;
- coping with how cancer affects your sexual functioning;
- coping with how cancer affects self-esteem and sense of self.

Seeing a psychologist is just like seeing any other health professional. It is an opportunity to talk with someone trained in emotional well being. It does not mean that you are weak or mentally ill. You can think together about different and perhaps more effective ways of coping with your issues and concerns about having cancer. Many people who have seen a psychologist say it is helpful to discuss their situation in confidence with someone outside of the family.
Where can I find a psychologist?

Every Hospital Trust in Birmingham has access to the cancer psychology service. This is based at the Cancer Centre of the Queen Elizabeth Hospital in Birmingham, but its psychologists also work in Sandwell General Hospital, City Hospital, Heartlands Hospital and Good Hope Hospital. The service employs qualified Clinical Psychologists and Counselling Psychologists who specialise in how cancer affects people’s psychological functioning and wellbeing. Some of these posts have been funded by Macmillan Cancer Support.

The cancer psychology service does not only see patients but also supports, trains and advises other health professionals working with cancer patients. It also supervises trainee clinical psychologists as part of their professional training and experience.

How can I get to see a psychologist?

If you want to talk to a psychologist, but this opportunity has not yet been offered to you, you can ask for this yourself. Simply ask the consultant or cancer nurse to refer you to the cancer psychology service.

What happens once I have been referred to a psychologist?

If you agree to see a psychologist, you will be sent an appointment letter. The appointment will normally be at the hospital closest to where you live; the appointment letter will tell you exactly where this will be. If it is easier for you to travel to another hospital, it can generally be arranged for you to see a psychologist there instead.

Chartered Psychologists are qualified psychologists who have had a minimum of six years of accredited training, and are approved by the British Psychological Society as professionally competent practitioners. Psychologists are NOT medical doctors like Psychiatrists; they do not prescribe medication, and do not admit people into hospital.

http://www.bps.org.uk/
What will happen at the appointment?

The first meeting is an opportunity for you to get to know the psychologist, to discuss the problems you would like help with, and to see if you would like to meet again. The appointment will usually last between 30 and 60 minutes. You can be seen by yourself, with your partner, or even with your whole family – the choice is yours.

After the first meeting you agree together whether to meet again, how often and for how many sessions. You will normally be offered between 1 and 6 appointments, or more if necessary. Appointments can be arranged for any time between 9am and 4pm on normal working days. Appointments may be on a regular basis e.g. weekly, fortnightly, monthly or just every now and again, depending on what you need. You can decide at any time that you no longer need an appointment, but please do let them know so that the available time can be given to another patient.

Some patients have found it particularly useful and supportive to share experiences with others going through similar difficulties, so group sessions are also regularly offered.
Background to the Cancer Psychology Referral Guidelines

Robin Paijmans AFBPS C. Psychol.
Macmillan Clinical Psychologist

Pan-Birmingham Cancer Psychology Service
Cancer Centre, Queen Elizabeth Hospital
University Hospital Birmingham, B15 2TH

cancer.psychology@uhb.nhs.uk

http://www.birminghamcancer.nhs.uk/