

Leicestershire Psycho-Oncology Service

Guide to the Service

NHS

Information for Staff

Leicestershire Partnership NHS Trust © 2004

Leicestershire Psycho-Oncology Service

Department of Liaison Psychiatry

Brandon Mental Health Unit

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NHS

NHS Trust

Key Points

Background

Psychological needs of patients with cancer are an essential component of medical care

About Psycho-Oncology

Patients usually want to be informed about and involved in their diagnosis and treatment

Psychological interventions are effective for those who have persistent distress and cancer

Organization of the Leicestershire Psycho-Oncology Service (LPOS)

The LPOS team works with all staff in improving the quality of life of cancer patients

We expect existing medical staff to initiate support and psychological treatment where needed

Referrals to the LPOS

We take referrals from all health professions, including GPs and counsellors

Use the referral form and referral guidelines (or include equivalent information in a letter)

Discuss the referral with the patient first, and refer only after they have given their agreement

Assessments

We will see inpatients within 8 working days and outpatients within 8 weeks of referral

A regular outpatient clinic is available in Clinic 14, Osborne Building, LRI

Advice

Staff can ring for advice about difficult problems on (0116 225-6218)

Introduction



This booklet introduces medical, nursing and allied professionals to the new psycho-oncology service in Leicestershire.

The Leicestershire Psycho-Oncology Service (abbreviated to the LPOS) is part of a new trend nationally, which recognises the psychological needs of patients with cancer. The NHS has only recently begun to address this need in a systematic way. Hence you will find that many individual trusts (and Strategic Health Authorities) have no access to a specialist psychiatric or psychological service for cancer patients at the current time. Leicestershire is one of the first areas to provide this service.

A few notes about this booklet. It is written for health and social care professionals in Leicester and Rutland who would like to know a bit more about the service. Although we are mindful that copies may be given to patients and families please remember that it is not a treatment or self-help manual. With the needs of health professionals in mind, we include a number of valuable resources such as referral guidelines in the appendices to this booklet. Several exciting new developments in Leicester and Rutland described here for the first time. One example is group therapy for patients with mood and adjustment disorders. Another is the availability of several treatment manuals that we hope will improve the quality of care by staff looking after patients with cancer and psychiatric complications. The first example is the new "depression and cancer" booklet.

We are proud of the new psycho-oncology service and hope that you find this information of value. We are committed to involving patients in treatment as much as possible, giving patients and families as much information as they request and using the "expert patient" as a valuable resource in our team.

We look forward to new service developments during 2004 and beyond.

Alex Mitchell, on behalf of the Leicestershire Psycho-Oncology Service
Liaison Psychiatry, Leicester General Hospital, Leicester, UK.

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Appendices (for your use as leaflets, scales or handouts)

- Appendix A – A Short Leaflet for Patients - Emotional Needs & Cancer
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The Psycho-oncology Service in Leicester

Summary and Mission Statement



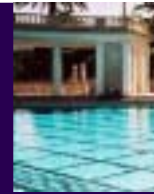
The Leicestershire Psycho-oncology service began formal operations in March, 2003 with the appointment of a consultant in liaison psychiatry (AJM). The MDT is to be completed by the appointment of a psychologist and one or more nurse specialists. The team base is the Leicester General Hospital, but we work closely with the Leicester Royal Infirmary, Leicester Glenfield Hospital and Leicestershire and Rutland Hospice (LOROS).

We will offer a comprehensive assessment and management service for people with psychiatric and psychological complications of cancer. We accept referrals by telephone, letter and fax and aim to respond efficiently to all requests. Typical response times are currently 1-2 days for inpatients and 6-8 weeks for outpatients. We are available to discuss complex or uncertain cases: 9am to 5pm five days per week. Out of hours, urgent cover is provided by the usual psychiatric duty doctor system in the respective sites.

We are committed to involving patients and families in their own management plan. We respect the wishes of all patients regarding disclosure of information and confidentiality but aim to have a full and honest discourse with patients and their families. We can already offer patients a range of treatment options in nearly all cases, and respect their right to discontinue or change treatment at their request (providing capacity and insight are preserved). We also offer patients the option to receive copies of medical correspondence where appropriate. We believe in the importance of high quality information, complementary medicine, the voluntary sector, self-help material and medical treatment for people with cancer, and will use or refer to these sources wherever possible.

We are committed to the principles of clinical governance (for example clinical audit and research) in order to continually improve the service for the benefit of patients and their families.

1. Background to the Service



1.1 Liaison Psychiatry Nationally

The Leicestershire Psycho-oncology Service (LPOS) has its roots in liaison psychiatry. Liaison psychiatry is recognized as a section of the Royal College of Psychiatrists. The college defines liaison psychiatry as “the sub-speciality of psychiatry whose function is to provide psychiatric services to General Hospital patients in A & E, medical wards and out-patient clinics. It focuses on the interface between psychological and physical health.”

1.2 The Psychiatric Needs of Medical Patients

Joint working parties of the Royal College of Psychiatrists with the British Association for Accident and Emergency Medicine,¹ the Royal College of Physicians² and the Royal College of Surgeons³ all recognise the need for the psychological care of A & E, medical and surgical patients. Improving the psychological health of medical and surgical in-patients and out-patients improves quality of life and reduces bed occupancy, investigations and procedural costs. Improvements in psychological care have also been shown to improve concordance, follow up attendance and physical outcomes.

Recommendations from the three Royal College documents are that acute medical services should purchase liaison psychiatry. The rate of psychiatric and psychological complications in those with physical disease has been widely reviewed and approaches 50% even when examined cross-sectionally (point prevalence) in many conditions.^{4 5}

1.3 Liaison Psychiatry in Leicester

Liaison psychiatry is a well established service in Leicester with a current base in the Leicester General Hospital. It was established nearly two decades ago and now comprises three consultants, several junior doctors and a full multidisciplinary team with administrative supportive.

What is Psycho-oncology?

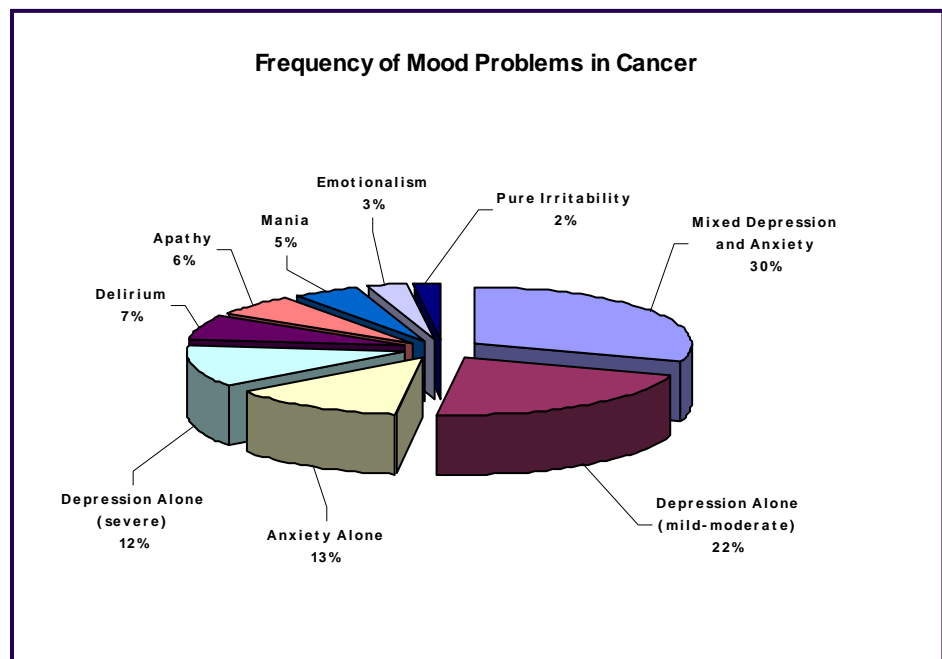


2.1 The Psychological Needs of Cancer Patients

There is increasingly recognition of the complex psychosocial needs of cancer patients.⁶ Although the published literature tends to concentrate on depression, common themes in people struggling with cancer include:

- Difficulty coming to terms with a feared diagnosis
- Problems coping with an uncertain future
- Issues about bereavement and loss
- Difficulty adapting to new changes in lifestyle
- Disagreements with professionals about suggested treatments
- Anger at delays, errors or poor communication of medical information

In addition a broad range of psychiatric complications are seen, including depression and anxiety (in any combination), mania (bipolar affective disorder), adjustment disorders, cognitive impairment and delirium and also psychoses (see figure 1).⁷



2.2 The Information Needs of Cancer Patients

Patients have always wished to be involved in their own care and increasingly clinicians are acknowledging what nursing colleagues have long recognized! Involving patients means informing them of the options at an early stage, pointing them towards relevant sources of information and engaging in a two-way dialogue.⁸

The National Cancer Director in association with the NHS information authority has drawn up the NHS Cancer Information Strategy, which aims to:

- Improve the effectiveness and efficiency of care delivery for those with actual or suspected cancer, throughout the patient journey.
- Support the implementation of the Calman-Hine national strategic framework for cancer services.
- Demonstrate the development of a disease-specific information strategy within the overall framework of Information for Health.

Studies regarding delivery of effective information for patients, are beginning to appear in the literature.⁹ We have adopted these principles in our service and aim to provide patients with as much information as they require in a format that most suits them.

2.3 Attitudes of the Medical Profession towards Cancer Patients

Doctor ⇔ patient communication has been better studied in the cancer field than probably any other area of medicine. Unfortunately, the results do not make encouraging reading. Two areas of difficulty are: 1. telling the patient the diagnosis of cancer and 2. revealing the likely survival time.

In 1961, 90% of US doctors indicated a preference for not telling a diagnosis of cancer but by 1979 this had been reduced to 3%.¹⁰ However, in a more recent study in Chicago, 77% of clinicians said they would give some estimate of prognosis "if the patient insisted" but even then over half said they would purposely give an optimistic estimate.¹¹ Practices clearly vary from country to country and are still far from perfect.^{12 13} For example, a recent survey of oncologists in Kuwait found that 79% would withhold the truth if family asked them to do so.¹⁴

We must remember that these are surveys of what health professionals would do. What do we actually do? In one examination of actual practice, clinicians told patients less than 70% of pre-agreed relevant information. Interestingly, patients later recalled less than 40% of what they were told.¹⁵ Clearly, there is room for improvement and LPOS will have a role locally in teaching communication skills to key professionals (see below).

Patients want their diagnosis and prognosis handled in a sensitive manner

2.4 Influencing Attitudes and Communication Skills of Professionals

Given the robust findings of problems with doctor ⇔ patient (and to a lesser extent nurse ⇔ patient) interaction,¹⁶ there is now some encouraging work on improving communication skills. Fourteen studies have examined interventions that aim to improve communication with cancer patients through educational sessions for medical staff (or allied health professionals). A similar number of studies have examined communications skills of nurses.¹⁷ One of the largest studies examined the influence upon oncologists.¹⁸ The results suggest that communication skills training is effective in improving the interaction between professional and patient and also improves satisfaction on both sides. Although no study has really got to grips with the effects on patient's wellbeing or psychiatric outcomes, we expect this will be shown in future work. This emphasises that careful communication is a cornerstone of clinical practice not just in the LPOS team but for all health and social care colleagues.

Communication skills training can improve clinical practice and patient satisfaction

2.5 Is Cancer a Special Case in Medicine?

The word cancer is universally known and widely feared by the public despite continuing good progress in medical treatments (see box 1).¹⁹ This impacts upon help seeking behaviour and screening success.²⁰ The disease is so feared that professionals will sometimes withhold the diagnosis from the sufferer, preferring to tell the family alone in what is sometimes called "a conspiracy of silence".²¹ The result can be a false and superficial cheerfulness and ongoing deception that does not permit patients an opportunity to express their concerns to others. Yet, it would appear that not all patients want to know their prognosis, at least initially. Research has shown that the shorter the survival prediction the more patients want to know this information.²² In addition, the tendency towards open disclosure has increased as patients have become more sophisticated and better informed about medical illnesses in general.

Box 1. Survey of US Public asking "Which Disease Are You Most Afraid of?"

Cancer 36%
 Cardiovascular Disease 23%
 AIDS 15%
 Diabetes 12%
 Obesity 10%

*11th Annual Research
 Conference of the American
 Institute for Cancer Research*

Cancer carries with it certain fears that, whilst not unique, are more widely considered by the public. For example, there is fear of death, pain, loss of independence or attractiveness, disability, sexual dysfunction, disruption of relationships and the suffering associated with progressive illness.²³

The end result is that patients with cancer bear a stigma not associated with heart disease or other illnesses, despite the fact that the actual prognosis and rates of complications may be little worse. Thus there is special justification for a dedicate branch of liaison psychiatry for this group of patients.

Cancer is widely misunderstood by the public, which leads to avoidance before a diagnosis and adjustment disorders after the diagnosis

2.6 Do Psychological, Psychiatric or Psychosocial Interventions Work?

Almost everyone working in this area acknowledges that psychosocial interventions for patients in distress are extremely effective. Yet there has been some recent controversy after one apparently well designed randomized controlled trial failed to show any extra benefit from a nursing intervention beyond usual care for patients with testicular cancer (Moynihan et al, 1998).²⁴ Closer inspection of this study shows that the psychological therapy was given regardless of psychological distress and that both outcome groups showed minimal depression at the end-point. In short the study indicates that specific psychological treatment is probably unnecessary in every cancer patient but is required for those in difficulty. This has now been recognized in several systematic reviews published recently.

This message is echoed in the 2003 National Institute of Clinical Excellence (NICE) guidelines on supportive and palliative care.²⁷

“Excellent evidence suggests that psychosocial interventions with cancer patients are important for enhancing coping and life quality for patients with cancer..... Different patient groups with different types or stages of diseases have different needs.studies show that individually tailored interventions such as the specialist nursing interventions or an interdisciplinary team seem to have a positive impact on psychological and physical functioning.”

2.7 National Expectation of a Psycho-oncology Service

Psychosocial care in cancer is now a high priority in the NHS, but this is a relatively recent development.²⁵ The NHS Cancer Plan for England was adopted locally in the Leicester Cancer Network Plan. In September 2000 the National Service Framework (NSF) for Cancer care was released.²⁶ This highlights several aspects relevant to psychological needs of cancer patients (including the acknowledgment that therapies are in desperately short supply), as well as the desire for better communication with primary care, better bereavement support and the vital need for more specialist nurses in this area. It also highlighted the fact that many patients found cancer support groups helpful. These recommendations and observations are echoed in the National Institute for Clinical Excellence (NICE) Guidelines for Supportive and Palliative Care For People With Cancer (above)²⁷ and in the Scottish Intercollegiate Guidelines Network publications.²⁸

In short, broad based psychological, supportive and educational interventions are now recognized as effective at reducing anxiety, depression as well as improving physical symptoms such as nausea, vomiting and pain in patients with cancer.²⁹ They should not be applied indiscriminately but rather should be considered on a case by case basis. Clinicians should have a high index of suspicion when patients are undergoing difficult procedures or in those who develop distressing complications. These aims are summarized in the Principles Of Good Service taken from The Calman-Hine Report from 1995 (box 2).³⁰

Box 2. Principles Of Good Service in The Calman-Hine Report

- High quality care, available to all, as close to home as possible
- Public and professional education to assist the early recognition of cancer symptoms, together with national screening programmes
- Clear information and assistance to patients and their families about options and outcomes
- Patient-centred services, taking account of patients' views and preferences
- Primary care involvement and good communication between different service providers at all stages
- Attention to psycho-social aspects of care at all stages
- Cancer registration and careful monitoring of treatment and outcomes

Patients should have access to high quality psycho-social care whenever needed

3. Organization of LPOS (who's who?)



3.1 Local Service Delivery

The national recommendations for good quality psychological care of cancer patients are now a reality in Leicester. As part of the Leicester Cancer Network Plan 2002 – 2005, funding was provided to develop a psycho-oncology team in close partnership with the existing liaison psychiatry service. The core team was envisaged as one part time consultant in liaison psychiatry, one full time psychologist and one or more nurse specialists. The LPOS began in March 2003 with the appointment of the first staff member. A base was identified in Leicester General Hospital with additional working space (clinic facilities) provided at the Leicester Royal Hospital. In the first three months of the service, considerable efforts were made to alert health care staff to the availability of the psycho-oncology team. This has resulted in a steady increase in referrals from both inpatient wards and outpatients, similar to that seen elsewhere.³¹ Close links have been forged with palliative medicine.

The service is now attempting to meet the psychological needs of patients with cancer in Leicester. Referrals come from many specialities that deal with cancer, such as dermatology, maxillofacial surgery, oncology, haematology, breast surgery, gynaecology, palliative medicine and general surgery. Referrals are initiated by a broad range of staff, including medical staff, specialist nurses, Macmillan nurses, counsellors and occupational therapists. A standardized referral form is available to help staff who are not sure what information to include (appendix C). Referral guidelines are also available, clarifying who and when to refer (appendix D).

Box 3. Core Principles of Leicester Psycho-Oncology Service

- Service to oncology, medical specialties dealing with cancer, and palliative medicine
- An open referral system for all staff
- Appropriate response based on need
- Assessment in hospital and in the community
- Interactive treatment course agreed with patients
- Joint working with other relevant services
- Treatment using the most minimally intrusive, yet effective method
- Service development involving users

3.2 Service Aims and Objectives

The service has several specific aims (table 1) and methods (table 2) illustrated in the following tables.

Table 1. Three Core Aims of the Leicester Psycho-oncology Service

| | |
|----|--|
| A. | To offer advice, education and training to all staff dealing with psychological complications of cancer. |
| B. | To offer a comprehensive service to patients with psychiatric complications of cancer. |
| C. | To work jointly with health professionals in improving communication in cancer care (including 'breaking bad news'). |

Table 2. – Nine Core Methods of the Leicester Psycho-oncology Service

| | |
|-----|--|
| A1. | We will take all requests for advice about psychological care and respond flexibly based on the perceived need. |
| A2. | We will work jointly with staff to improve the front line recognition and treatment of distress. |
| A3. | We will consider all requests for training of staff re: communication, recognition and management of psychological and psychiatric issues and bereavement care. |
| B1. | We will see all referrals for mood disorder (depression, anxiety, anger, irritability, euphoria) in cancer patients requiring a specialist opinion within 8 weeks for outpatients and 1 week for inpatients. |
| B2. | We will see all referrals for cognitive impairment, psychosis or delirium in cancer patients requiring specialist opinion within 4 weeks for outpatients and 1 week for inpatients. |
| B3. | We will see all referrals for severe 'adjustment to bad news' issues 8 weeks or more after a diagnosis of cancer where a specialist opinion is requested. |
| C1. | We will aim to deliver high quality communication in cancer care in our own team. |
| C2. | We will work with other clinicians in setting up workshops on breaking bad news for other staff. |
| C3. | We will develop a local working document / policy on good quality communication in cancer care. |

3.3 Hierarchy of Needs and Responses

The Leicestershire model of psycho-oncology care has already learned lessons from established psycho-oncology services in the UK. One useful premise is the concept of a hierarchy of need for patients married to an appropriate response.³² Patients prefer the majority of emotional needs to be met by their own family / care-givers and the front line staff rather than a specialist service. Thus it professionals should be able to ask the question 'How do you feel?' and should be able and willing to deal with an honest answer. All staff should be empathic and supportive with patients – a task which might require more time than expected (level 1 of care, table 3 below). All staff should be able to provide (or direct the patient towards) accurate information about their diagnosis, its complications and its treatment (level 2 of care, table 3 below). About a third of patients may require short-term basic psychological interventions such as crisis management support. These needs can be met by existing staff given adequate guidance and support (level 3). Perhaps less than 10% of patients require more specialist psychological work. Such needs could be addressed by those with formal counselling training or nurse specialists who have undertaken a training program. We are trying to develop just such a program locally. The final level of complex psychiatric needs should be dealt with directly by the psycho-oncology team.

Table 3 - Care Needs and Care Providers for Cancer Related Distress

| Level of care | Identified Need | Who provides Care? |
|---------------|---|---|
| 1 | General emotional care (empathy) and support | All staff |
| 2 | Information, accurately and sensitively delivered at a time and in manner consistent with patient need. | All staff |
| 3 | Short-term, focussed 'non-psychotherapeutic' interventions, crisis management | Role-enhanced Staff |
| 4 | Specialist psychological work | Specialist counsellors, Trained Nurses Specialists |
| 5 | Formal specialist psychological and/or psychiatric intervention | Psycho-oncology team |

4. Referrals to the LPOS

(How and who to refer)



4.1 Appropriate Referrals – Psychiatric Problems of Cancer

We will see all mental health disorders associated with significant distress in patients with cancer, where the cancer (or perceptions of cancer) are closely related to the onset or course of the mental health problem. We will also see cases of uncertain origin, where this is suspected to be the case.

4.2 Appropriate Referrals – Psychological Problems of Cancer

Cancer causes a wide range of psychological problems that often blur with psychiatric diagnoses. They may or may not fit into a medical model. Examples include distress after a recent diagnosis of cancer, problems coping with cancer, problems facing end of life decisions, problems relating to consent to medical treatment and problems relating to family and friends after a diagnosis of cancer. Such cases may be best dealt with by existing cancer staff (e.g. nurse specialists) or counsellors. Where doubt exist please seek advice from us.

4.3 Inappropriate Referrals – General Problems Unrelated to Cancer

Any psychiatric diagnosis which is unrelated to cancer (even if cancer is present) is not a source of appropriate referral. Further, we would expect that clinicians and MDT staff are able to begin treatment for depression and adjustment disorders in the first instance. If such patients do not respond, it would be reasonable to refer. Communication issues between medical staff and patients (alone) are not usually a good reason for referral. Similarly, although we are happy to advise on issues regarding capacity to consent and treatment refusal (*see section 5.1 for further information*), this is not usually reason to justify referral. Any pre-existing psychiatric disorder, without contribution of cancer, should be referred to the appropriate sector psychiatric team.

4.4 Inappropriate Referrals – Relatives of Patients

Where a patient is already known to our service we will assess and manage distress in relatives at our discretion. During 2004 we are not aiming to see relatives of patients who are not known to us. As the team expands we may broaden our remit to include these relatives.

4.5 Alternatives to Referral

There are a wide range of alternatives to referral to the LPOS, both statutory and voluntary. Broadly, social issues may be best dealt with by social services, spiritual issues by the chaplaincy service, and pure adjustment problems by one of the counselling teams. However, we often work together with these agencies and therefore a joint referral may be appropriate (see section 7).

4.6 How To Refer

We accept referrals from any professional (GP, nurse, counsellor, doctor) but ask for basic information about the reason for referral and the background factors. A referral can be made by letter, telephone (225-6218) or fax (225-6173). If preferred, a standardized form is available which highlights the necessary information (appendix C). Referrals should be discussed with the responsible medical/surgical consultant before referring.

Please indicate (and justify) the urgency of the referral as this will influence our response. In all cases of psychiatric emergencies, please telephone first.

A summary of the current referral guidelines is included in appendix D.

A decision aid, to aid referrers to our service is shown in appendix E.

4.6 Overview of the LPOS Patient Pathway

An overview of the service from the perspective of the patient is illustrated in following figure.

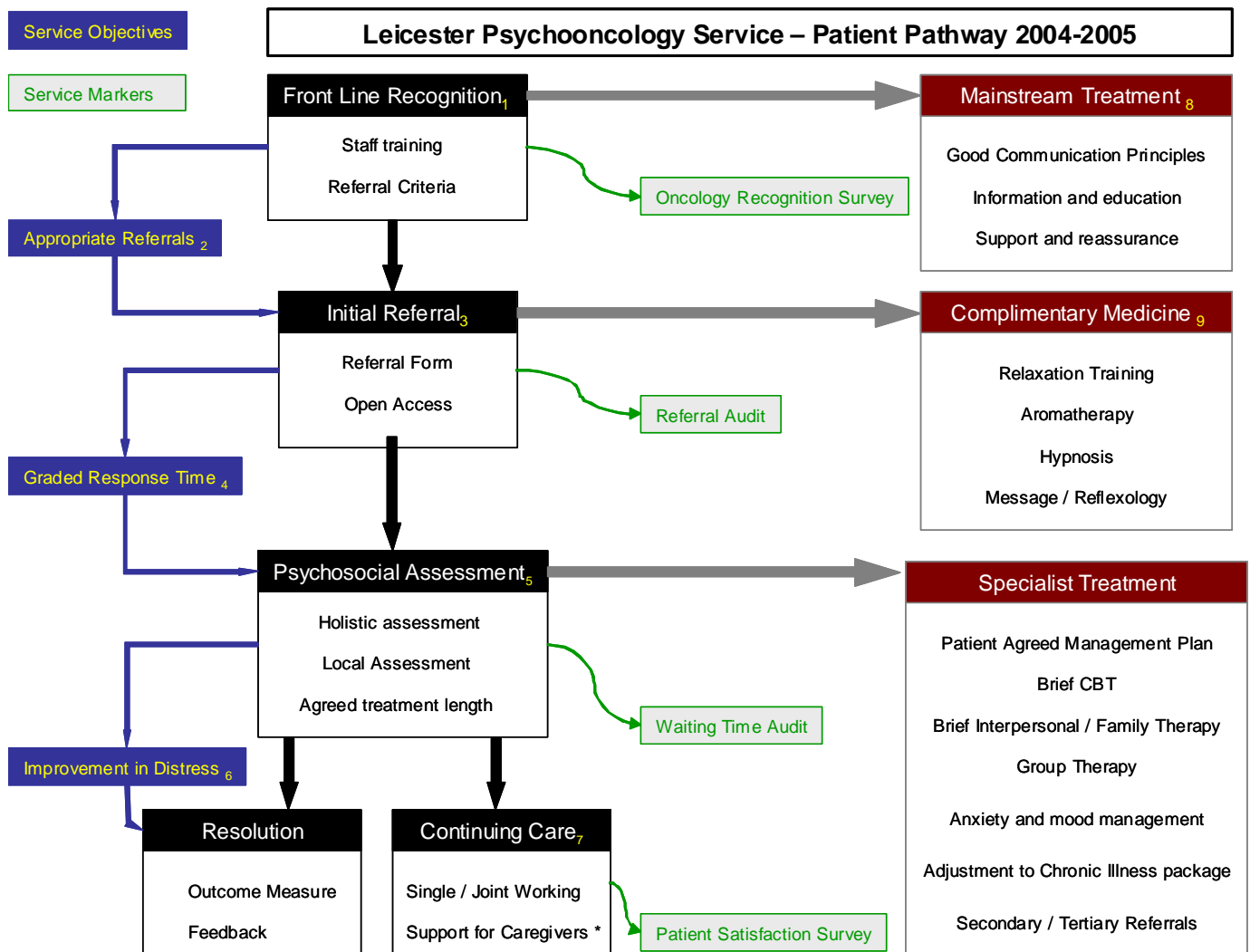


Figure 2 Notes

- All staff dealing with cancer patients should be able to detect distress appropriately.
- Guidelines on appropriate referrals are included under **appendix D**.
- A standardized referral form is included under **appendix C**.
- We offer a response time based on the need of the patient (see **mission statement**).
- Assessment will be from a member of the psycho-oncology team, and includes an agreed treatment plan and duration with the patient (where possible).
- A survey of distress and coping at baseline and after assessment is ongoing
- For those requiring continuing care, various options should be available including – medical follow up, nursing support, psychological interventions.
- Mainstream management for commonly encountered distress should be offered by all staff in oncology and related fields (see **section 3.3**)
- Complementary medicine is an option favoured by many cancer patients and should be offered as part of an integrated package.

5. Difficult Clinical Scenarios (Clinical Advice)



5.1 Treatment Refusal, Capacity and Consent

At least 12% of patients say they would refuse potentially life saving treatment if it caused a severe but temporary burden.³³ Reasons for treatment refusal are complex (see figure 3). In law, capacity is judged to be intact until proven otherwise. Where a patient is unable to understand a proposed treatment, it is usually appropriate to act in the person's best interests (providing there is no relevant advance directive or "living will"). Not uncommonly, it is not certain whether a person is able to understand and weigh the pros and cons of a decision. In these cases capacity should be explicitly assessed and the results recorded in the medical notes (see appendix B). Patient with capacity will sometimes refuse treatment because they do not adequately understand what is being proposed. In these cases, more time is needed to be spent with that person. However, in the case of someone with capacity, who understands the treatment under consideration but who honestly believes that the risks outweigh the benefits, then the right to refuse treatment must be respected. For example, it is not uncommon for patients to refuse palliative chemotherapy because they choose not to endure further adverse effects.

Unfortunately, this issue is complicated in two situations. 1. When capacity is not preserved. 2. When mental illness is suspected.³⁴ If a patient lacks capacity then refusal of treatment can be overridden if absolutely necessary (again not where there is an advance directive) but follow up explanation must be given to the patient. This is exceptional and in most cases of disagreements over treatment, refusal is rational, not irrational.³⁵ In cases where mental illness is the cause of treatment refusal (eg "my future is hopeless and treatment is futile") we recommend that you should seek advice from our service.

Do not assume refusal of treatment is irrational, explore this with the patient

5.2 Patients Who Are Angry or Irritable

Anger is a very common and in many cases a normal reaction to bad-news. In most people this is apparent as an increase in irritability and verbal outbursts, but it can deteriorate into combativeness or violence. Anger can be directed towards the self ("I hate myself like this"), staff ("You are all useless") or most commonly the family ("You don't care for me anymore!"). In most cases, the person needs time and space to express their feelings and gradually come to terms with their fears. The principles of sensible support and information (See table 3, levels 1-3) apply. Depression, anxiety, pathological grief, alcohol use and mania are all psychiatric reasons which predispose to anger. Rarely, CNS lesions predispose to recurrent anger and disinhibition, a particularly unfortunate combination.

Anger during medical treatment often signifies distress and the need for help

5.3 Psychiatric Emergencies, Suicide and the Mental Health Act

Disturbed behaviour, florid psychotic presentations, mania and retarded depressions are very serious psychiatric disorders requiring prompt treatment. In these cases we would recommend telephoning for advice as soon as possible, ideally the same day. We will try and respond equally quickly. About 10-20% of unselected recently diagnosed patients and most depressed patients express suicidal thoughts.³⁶ In most cases this is an expression of distress not a true intent to die, and signals that more help may be needed.

Many cases of delirium present with changes in behaviour or higher function (e.g. clouding of consciousness, agitation, treatment refusal) and although equally urgent, are almost invariably due to an underlying physical cause. In such cases we are happy to advise on symptomatic control of symptoms, but medical investigation and treatment must continue on the medical wards.

Where patients clearly require psychiatric treatment, against their wishes, and no alternative is available, the mental health act may be used. This can give permission to hold, investigate and treat the psychiatric disorder for a period of 72 hours (section 4 or 5) or longer (section 2 or 3). This is really a treatment of last resort.

6. Service Standards (Clinical Governance)



6.1 Current Standards

Any new service needs a mechanism in place by which progress can be monitored. We are keen that the LPOS is open to the principles of clinical governance, as we believe this will enhance progress in the future. In addition, monitoring (supervision) structures within the team will enhance the ongoing quality of patient care.

From the start of the service, we have put several systems in place that make monitoring of the quality of the service possible. These are:

- ✓ a specialised database that logs all referrals
- ✓ a forum for regular case review
- ✓ weekly supervision for junior staff in the team
- ✓ weekly supervision for nursing staff in the team
- ✓ the routine use of a satisfaction questionnaire for all patient contacts.

6.2 Future Standards

We propose a number of additional mechanisms that will enhance standards and developments in psycho-oncology.

1. A simple survey of recognition of depression and anxiety by front-line staff in oncology. This will answer the question, is the need in this population being adequately recognized?

2. An ongoing audit of referrals to examine the source, number and type of requests received. This will answer the question, are referrals being sent appropriately to the service?

3. Examining the waiting time for patients referred to us, as inpatients, outpatients or from other services (e.g. LOROS). This will answer the question, are we responding appropriately to referrals?

7. Working with Other Agencies and Professionals (inter-agency work)



7.1 Working with Other Health Professionals in Cancer Care

Our fundamental model of care suggests that about 10% of people with psychological complications of cancer should be referred. In the case of these referrals we have an open referral policy, meaning any healthcare professional can refer to us directly. That said, we believe that a substantial proportion of cases can be appropriately managed by health professionals such as Macmillan nurses and other cancer nurse specialists, medical staff or other multidisciplinary team members. Indeed, patients often expressly do not wish to see a psychiatrist for such problems and prefer existing team members.

For this reason, we see part of the role of psycho-oncology as assisting these “front-line” staff in dealing with a variety of psychological issues. In many cases, team members are perfectly competent and confident about managing problems like distress after bad news, effects on family and friends and fears about the future. In other cases, we are happy to be a source of advice. We are also involved in staff training pertaining to the detection and management of distress in cancer care. Several of the assessment tools at the back of this booklet may be of use to staff looking after such patients themselves.

7.2 Working with General Practitioners

GPs have an important role in psycho-oncology, as in other fields of medicine. This is particularly the case with respect to continuity of care and palliative care in the community. Often after discharge from hospital, GPs are the main source of contact for patients, and further, have an overview of all the medical disciplines that others may not have. We are committed to working closely with primary care to further the holistic management of patients with psychological needs. We will also accept referrals direct from primary care, usually for assessment in the outpatient department.

7.3 Working with Counselling Services

Perhaps more than in any other branch of medicine – the need for counselling has been established in cancer care and furthermore the evidence base to support it is good (for example see Maguire, 1980).³⁷ For these reasons we are keen to work closely with counsellors in the field of cancer care. In Leicester there are two excellent counselling services for people with cancer, but with slightly different remits.

A. The “Coping with Cancer” Service at Helen Webb House offers a variety of support services to people with cancer and their families. It is funded from Primary Care Trusts and charity work. All counsellors have formal professional accreditation. They can be contacted on 0116 2230055.

B. The “LOROS counselling service” at the Leicestershire and Rutland Hospice is a long established service now funded by LOROS. It offers a comprehensive assessment and treatment package to those with cancer, including patients in the terminal stages of illness. They will see people outside LOROS if required.

7.4 Working with Psychiatric Services

It should not be forgotten that the psycho-oncology service will require the assistance of established psychiatric services from time to time. For the most part this will be provided via liaison psychiatry (Leicestershire Partnership Trust) for example pertaining to hospital admissions, mental health nursing, or mental health act assessments. In some cases day hospital or outpatient facilities will be required, distinct from the facilities available at the Leicester Royal Infirmary.

8. Improving the Service (Aims for the Future)



8.1 Vision for the Near Future

The core values, aims and remit of the service will continue, but we are planning the following valuable developments:

- We aim to offer a comprehensive service to relatives of patients with cancer (including bereavement care).
- We will aim to develop an evidence based group therapy type intervention for patients with psychological complications.
- We would like to create a teaching video / Cd-rom about communication in cancer care and breaking bad news.
- We will be developing a training package for health and social care professionals who wish to develop specialist clinical skills in this area.

8.2 Vision for the Further Future

What might the LPOS offer in years to come? One exciting prospect is expansion of the core team to include professionals with different skills and styles. Nursing interventions already complement psychological and psychiatric intervention. Input from a family specialist or social worker would also be a major advantage. The kind of service offered to patients could also then be broadened, to include not only moderate to severe persistent distress, but early distress perhaps soon after receiving bad news (a diagnosis of cancer). This is likely to have a preventative role in preventing the degree and frequency of complications of such a feared diagnosis – ultimately reducing the prevalence of psychiatric complications in cancer.

A further possible development, is housing the developing psycho-oncology team in a building near to the point of oncology assessment and treatment. We envisage a mental health and wellbeing clinic that is always open within the Osborne building (or future equivalent) that could take urgent referrals, drop-ins and routine cases for a variety of non-threatening interventions soon after medical diagnosis. This would truly represent a comprehensive, flexible and efficient service for patients with cancer in Leicestershire.



Background

This leaflet explains a little about the care of people with cancer in Leicester and Rutland. We believe it is important to address the psychological and emotional wellbeing of people, as well as their physical needs. Recently a new service has been set up designed to do just that. It is called the Leicestershire Psycho-oncology Service. "Psyche" relating to the mind, and "oncology" relating to cancer.

Why Have You Been Given this Leaflet?

You have probably been given this leaflet because your doctors or nurses are considering asking you to come and talk to us. Occasionally people don't want to come because they don't like the idea of seeing someone new, or perhaps they don't want to talk about their illness anymore than absolutely necessary. In truth we run a very down-to-earth service for people with a variety of emotional complications after a diagnosis of cancer. We respect the wishes of people who do not want to be seen by us, as there are alternatives such as written information, counselling, spiritual support or complementary therapies. However, most people who come to see us say that they have benefited.

Who Are We?

Our team consists of health care professionals with a special interest in the mind and body including nurse specialists, psychologists and psychiatrists. We will ask about your physical and psychological health and will probably make some suggestions to you which you are free to take or leave. We recognize it is often very hard to see yet another professional, but we like to think we offer a service you will not get elsewhere and further, we have a lot of experience of dealing with sensitive issues. Many worries relating to cancer can be painful, such as, is my diagnosis correct? What does the future hold? and what should I tell my family or friends?

Taking Things Further

If you want to discuss things further with your own team before seeing us, please feel free to do so. If you want to come and see us in the future but not now, or simply would like some information about emotional complications of cancer, please contact us on (0116)225-6218 or via your general practitioner.

Appendix B LPOS Capacity Form

Photocopy



"6-Step" Assessment of Capacity Form for Medical Staff

www.leicestershirepartnership.nhs.uk | 11 Oct 2019

| | | |
|----------------|------------|--------------------------|
| Patient Name | DOB | A&E/Hospital No. |
| Assessors Name | Consultant | Assessment Date and Time |

Tick when Completed

| 1 List Details of Proposed Procedure You intend to Explain | Checklist |
|--|---|
| | Incl. The type of procedure or treatment |
| | Incl. The reason for the treatment |
| | Incl. reasons for / against the treatment |
| | Incl. Possible complications |

| 2 Assess Patients Ability to Understand General Information | Checklist |
|---|--|
| | Explained in appropriate language? |
| | Consciousness is unimpaired? |
| | Is able to concentrate and hear clearly? |
| | Is able to retain the information? |

| 3 Assess the Patients Ability to Understand THIS Information | Checklist |
|--|---------------------------------|
| | Recalls nature of procedure? |
| | Cites pros and cons? |
| | Retains information? |
| | Believe information to be true? |

| 4 Exclude any Psychiatric influences | Checklist |
|--------------------------------------|---|
| | No Psychosis (odd thinking or beliefs)? |
| | No Dementia (memory, odd behaviour)? |
| | No Delirium (poor attention)? |
| | No Depression (Guilt, self-esteem)? |

| 5 Exclude any BIASES / Coercion | Checklist |
|---------------------------------|----------------------------|
| | No coercive family member? |
| | No coercive staff member? |
| | No other Coercive factors? |

| 6 Explain Dynamic Nature of Consent | Checklist |
|-------------------------------------|---|
| | Incl. consent can be withdrawn |
| | Incl. alternatives may be available |
| | Incl. Withdrawal of consent will not automatically prejudice case |

| Consent (Explanation if required) | Outcome |
|-----------------------------------|------------------------------------|
| | Lacks Capacity => Best Interest |
| | Has Capacity => Refuses |
| | Has Capacity => Accepts treatment |
| | Mental Health Issue |
| | Capacity Uncertain => Reassessment |

| | |
|---------------------|------|
| Your Signature | Date |
| Patient's Signature | Date |
| Witness Signature | Date |

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Appendix C LPOS Referral Form

Photocopy



Leicester Psychooncology Service (LPOS) – Referral Form

doi:10.1136/bmjopen-2014-005490

| | | | |
|---|----------------|------------|------------------------|
| 1 | Patient Name | DOB | Current Ward |
| 2 | Referrers Name | Consultant | Referral Date and Time |

Please complete in as much detail as possible

| | | |
|---|--|---|
| 3 | What is the reason for referral? | Prompt |
| | | Anxious (Agitated, panic, PTSD)? |
| | | Depression (low interest, self-esteem)? |
| | | Delirium (poor orientation or attention)? |
| | | Behaviour (non-compliance, disruptive)? |
| | | Uncertain / Other? |

| | | |
|---|--|----------------------|
| 4 | What is the history of the cancer / tumour? | Prompt |
| | | Site? |
| | | Stage? |
| | | Treatment cycle etc? |
| | | Prognosis? |

| | | |
|---|---|-----------------------------|
| 5 | What is the remaining medical history? | Prompt |
| | | Other disorders? |
| | | Other treatment? |
| | | Any Pain? |
| | | Any liver or renal disease? |

| | | |
|---|--|-------------------------------|
| 6 | What are the background factors? | Prompt |
| | | Past Psychiatric history? |
| | | Social support? |
| | | Alcohol or Illicit Drug User? |
| | | Difficult Personal History? |
| | | Previous Self-Harm? |

| | | |
|---|---|------------------------------|
| 7 | What is the patient's understanding of their cancer? | Prompt |
| | | Has been told diagnosis? |
| | | Understands the diagnosis? |
| | | Has been told the prognosis? |
| | | Understands the prognosis? |

| | | |
|---|---|-----------------------------|
| 8 | What kind of psychiatric/psychological treatment has been offered? | Prompt |
| | | Information / Education |
| | | Support (from who)? |
| | | Medication (specify which)? |
| | | Counselling or similar? |

| | | |
|---|--|-------------------------------------|
| 9 | Is the patient appropriate for LPOS and agreeable for assessment? | Prompt |
| | | Please see LPOS Referral Guidelines |
| | | Consider other options first |
| | | Explain purpose of referral to LPOS |
| | | Current Suicidal Intent? |


| | | | | | |
|--------------------------------|--------------------------|----------|--------------------------|------------|--------------------------|
| 10 State Desired Response Time | | | | | |
| "Routine" | | "Rapid" | | "Urgent" | |
| 7+ days | <input type="checkbox"/> | 1-7 days | <input type="checkbox"/> | < 48 hours | <input type="checkbox"/> |
| | <input type="text"/> | | <input type="text"/> | | <input type="text"/> |
| | Why? | | Why? | | Why? |

If appropriate, please refer to:
LPOS, Department of Liaison Psychiatry
Brandon Unit, Leicester General Hospital
In hours: ☎ (0116) 225-6218 or Fax - 6173
Out of hours: page Duty @ SHO



Guidelines for Referring Patients to the LPOS

©2014 Guidelines: dx.doi.org/10.1093/ncp/ncn014 13 Nov 14

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Is there significant psychiatric or psychological concern in a patient with cancer?

- Eg. Persistent distress
- Eg. Psychiatric illness
- Eg. Suspected problem but difficult assessment
- Eg. Not Coping

- ➔
- ➔
- ➔
- ➔

Notes for Guidance

- Please screen to find out why*
- Specify nature and duration*
- Please ring us to discuss*
- Consider involving social services*

CONCERN



Is the patient appropriate for the LPOS?

- If patient is under 17 years old (or 18 years if Full Time Educ.)
- If over 16 years (including those over 65 years old)
- Cancer suspected to have caused or exacerbated the distress
- Other special circumstances

- ➔
- ➔
- ➔
- ➔

Notes for Guidance

- Refer to Child & Adolescent Psychiatry*
- We will see these referrals*
- If cancer is an incidental finding, refer to sector ψ*
- Please ring us to discuss*

APPROPRIATE



Where is the patient likely to need to be seen?

- As an inpatient (including LOROS inpatients)
- As an outpatient (including LOROS outpatients)

- ➔
- ➔

Notes for Guidance

- Please refer by phone (+/- letter or fax)*
- Please refer by letter (+/- phone)*

FIRST CONSIDER



Are other sources of support and cancer care appropriate?

- Professional
- Counselling
- Information & Self-help (eg Cancer information centre)

- ➔
- ➔
- ➔

Notes for Guidance

- GP, Sector ψ, Nurse specialists / Macmillan*
- Coping with Cancer, LOROS Counselling*
- Please ask if unsure what is available*

THEN



Referral to the Leicestershire Psycho-oncology Service

- Use LPOS Referral Form for Medical Staff
- Referrals accepted between 9am to 5pm
- If unsure (or in an emergency)

- ➔
- ➔
- ➔

Notes for Guidance

- Keep a copy in the notes (and fax form if urgent)*
- Out of hours, Sleep Duty ψ SHO if urgent*
- Ring to discuss*

LPOS Dept. Liaison Psychiatry (0116) 225-6218
Brandon Unit, Leicester General Hospital, Leicester LE5 4PW

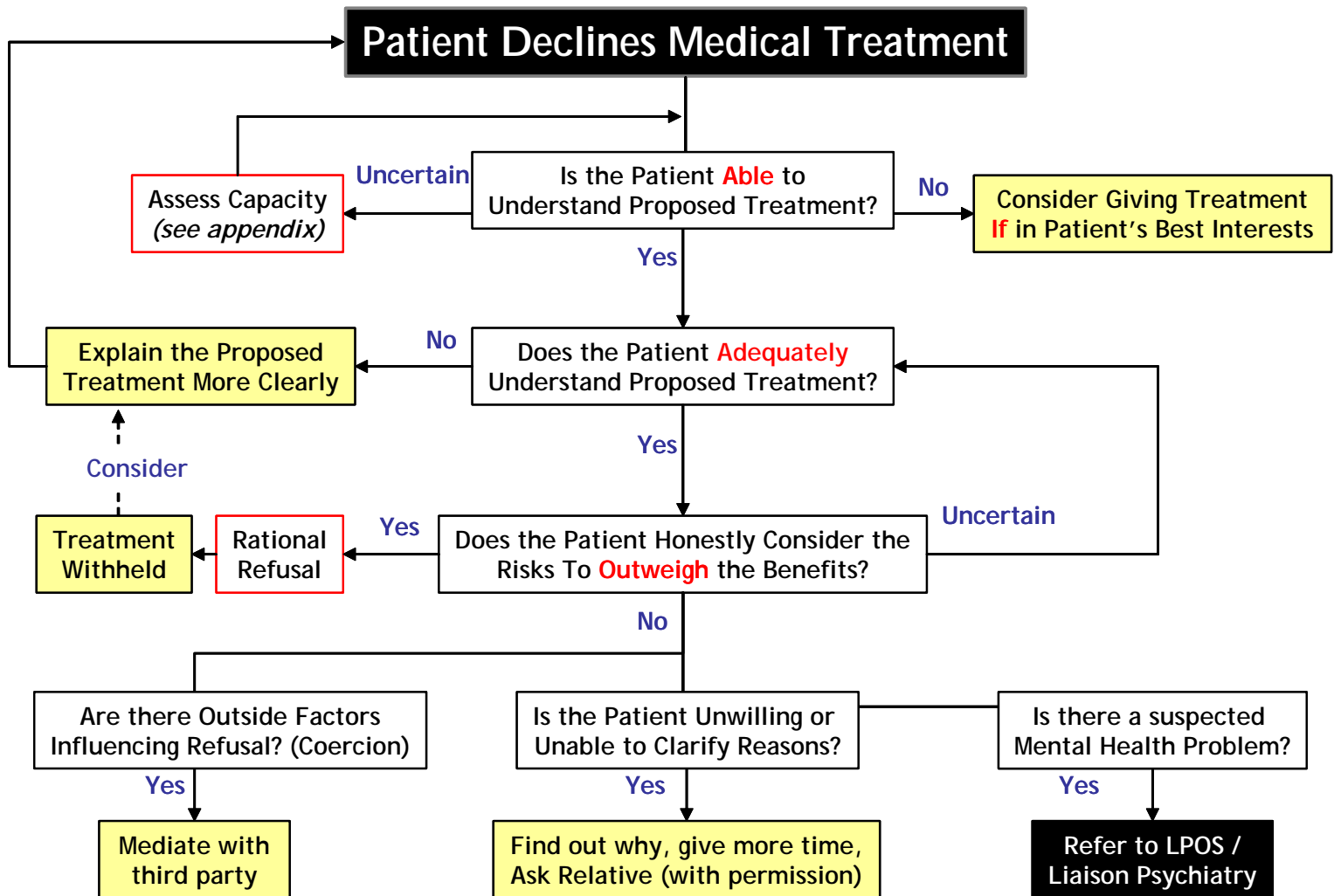
Coping with Cancer (0116) 2230055
LOROS Counselling (0116) 2313771

Appendix E Illustrated Referral Guidelines

Decision Aid for Treatment Refusal



Figure 3. - Decision Aid in Psycho-Oncology - "Treatment Refusal"



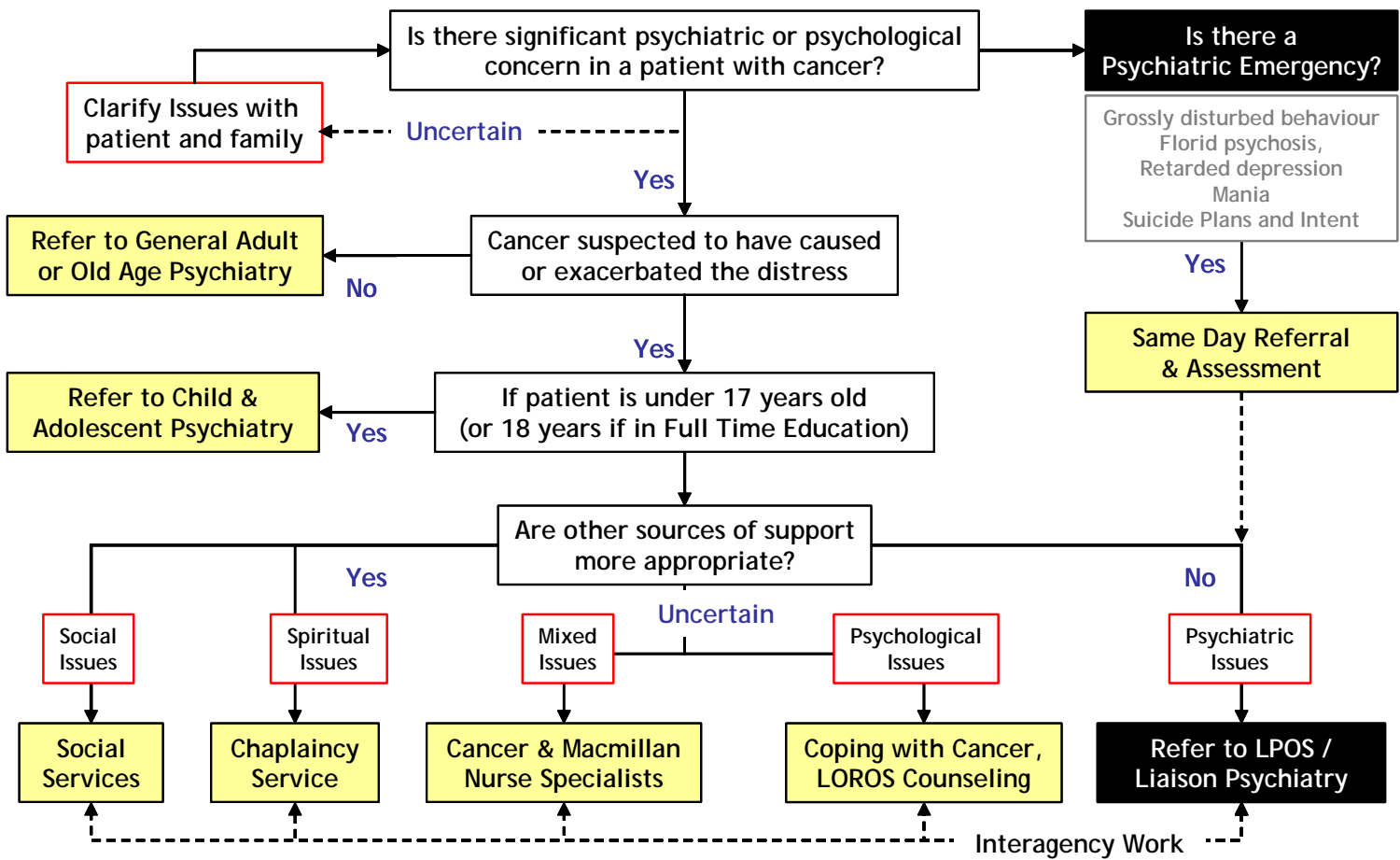
Appendix F Illustrated Referral Guidelines

Decision Aid for New Referrals



Figure 4. Decision Aid in Psycho-Oncology - "New Referrals"

Referral Guidelines for Psycho-oncology



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Guide to the LPOS

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