Management of Adverse Effects following Breast Radiotherapy

Maher Committee
The Royal College of Radiologists

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The Maher Committee is a multidisciplinary committee set up in July 1994 under the auspices of the Royal College of Radiologists at the request of the Department of Health; the Chairman is Dr E J Maher, Consultant Oncologist, Mount Vernon Centre for Cancer Treatment, Northwood HA6 2RN, UK. This report was presented to the Board of the Faculty of Clinical Oncology of the Royal College of Radiologists on 3 February 1995.

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Contents

1 Introduction

Patients treated for breast cancer may suffer a range of upper limb problems, from mild oedema and inner arm sensation changes related to surgery, to the rare but severely disabling brachial plexus neuropathy associated with radiation damage brought to public attention by a group of patients, Radiation Action Group Exposure (RAGE), who claim to have suffered such damage. As a result of a House of Lords debate (May 1994), Baroness Cumberlege undertook that a committee would be set up to consider how women with axillary tunnel damage associated with radiation should be managed. Accordingly a multidisciplinary committee was set up in July 1994 under the auspices of the Royal College of Radiologists. The chairman is Dr EJ Maher, Consultant Oncologist, Mount Vernon Centre for Cancer Treatment. This is their report, which was presented to the Board of the Faculty of Clinical Oncology of the Royal College of Radiologists on 3 February 1995.

1.1 The terms of reference of the committee

a) To make an assessment of the optimum management of women who have suffered axillary tunnel damage following radiotherapy for breast cancer and of the current availability of specialist services for such management.

b) To make recommendations on how services for this group of women can best be organised with regard to the outcome of the document *A Policy Framework for Commissioning Cancer Services* (May 1994)

c) To report through the Faculty Board of the Royal College of Radiologists, the Joint Council of Clinical Oncology and then to the Chief Medical Officer. The report would then be submitted to the Clinical Outcomes Group of the Department of Health.

1.2 The composition of the committee

Dr David Butler	CRMF/Bucks FHSA; Facilitator in Palliative Medicine (former GP)
Dr Carol Davis	Senior Lecturer in Palliative Care, Countess Mountbatten House, Southampton
Ms Margaret Forrest	RAGE committee member
Ms Eileen Gough	Information Services Manager, Breast Cancer Care
Gail Hewlett	Secretary
Dr Ian Kunkler	Consultant Oncologist, Western General Hospital, Edinburgh
Dr Jane Maher (Chairman)	Consultant Oncologist, Mount Vernon Centre for Cancer Treatment
Ms Jan Millington	Chairman, RAGE
Ms Gill Oliver	Director of Patient Services, Clatterbridge Centre for Oncology, Wirral
Ms Marianne Rigge	Director, College of Health
Ms Jackie Todd	Physiotherapist, Ardenlea Marie Curie Centre, British Lymphology Interest Group (BLIG) representative
Dr Patricia Wilkie	Acting Chair, the Patients Association
Dr Elizabeth Wilson	Department of Health (observer)
Ms Judy Young	formerly Superintendent Radiographer, St Bartholomews; Manager, Lynda Jackson Cancer Support and Information Centre

The Committee is grateful for the assistance it received from several individuals who prepared papers on particular topics to inform its work: Robin Grant, Edinburgh (the role of the neurologist); Chris Fisher, Edinburgh (the role of the neurophysiologist); Helen Luke, Edinburgh (role of occupational therapies); Rolfe Birch, Royal National Orthopaedic, Stanmore (role of specialist surgical intervention); and Frank Kurer, The National Hospital for Neurology and Neurosurgery (role of pain clinics).

2 What is axillary tunnel damage?

The term axillary tunnel damage (as used in the terms of reference) is not commonly used in the literature. For this report it has been interpreted as describing the spectrum of problems associated with damage to tissues adjacent to the clavicle and under the armpit due to treatment with ionising radiation. The most serious complication is generally acknowledged to be damage to the nerve cords, i.e. radiation induced brachial plexopathy (RIBP).

Assessment of optimal management and current availability of specialist services is based on three sources of information:

1. Consultation with RAGE (Appendix I).
2. Literature review (Appendix II).
3. Consultation with individual experts and organisations (Appendix III).

Dr Maher met formally with RAGE on 30 August 1994 and agreed to delay convening the committee until the results of a RAGE survey were available (Appendix I) and the AGM had been held. The Committee met on 4 November and 2 December and an additional meeting was held with the directors of BACUP, CancerLink and Breast Cancer Care, and the College of Health to discuss the production of an information leaflet and directory of key services to be accessible to patients as well as health care professionals.

The committee recognises that the true scale of radiation morbidity among members of RAGE would require an evaluation of clinical details and investigations of all those claiming to be damaged by radiation. Surgery, chemotherapy, recurrent cancer or other unrelated conditions may play a part in the pathogenesis of their problems and their relative contributions may be difficult or impossible to assess.

Review of the literature reveals no completely unambiguous guidelines as to diagnosis or management of RIBP and associated problems and most studies are based on small series of selected cases considered retrospectively, rather than large prospective randomised trials. There is thus no solid research base. The committee has taken the view that, in spite of acknowledged limitations, the views of sufferers, as represented by RAGE, should be paramount in recommendation of services and it has been guided by the priorities identified by the RAGE committee.

3 Assessment of need and available services

The chief problems reported were those of unrelieved pain, characteristically neuropathic in character, and paralysis of the hand and then of the whole arm. Further complications included bone pain and necrosis, lung damage, severe fibrosis and lymphoedema.

For RAGE members one of the worst deficiencies was the denial that there might be a problem, which compounded the real anger they felt at not being warned of possible dangers of radiotherapy treatment.

Patients reported difficulties in obtaining a diagnosis or even information about the condition. When a provisional diagnosis of RIBP had been made, those with skills to deal with symptoms, were inadequately informed as to the natural history and other problems associated with RIBP. There appeared to be no structured management plan, with problems in gaining access to expert help at the different stages of progression of the condition, in particular, pain management and access to occupational therapy, including aids to daily living. There was also a failure to provide psychological support. In the absence of organised services, an unacceptable burden was falling on a few RAGE committee members to provide both information and support while coping with their own disabilities. The national voluntary organisations CancerLink, BACUP and Breast Cancer Care had relatively little information on RIBP.

The RAGE survey reported some good practice. A number of health care professionals had been helpful. In particular, pools of expertise were to be found in cancer treatment units, palliative care units and pain clinics but there was poor communication between them, no clear protocols and difficulties in patient access. Based on perceived shortfalls, information was collated on:

• Organisation of a coordinated professional network	Ian Kunkler, Edinburgh
• Role of neurologist in diagnosis	Robin Grant, Edinburgh
• Role of Neurophysiologist in diagnosis	Chris Fisher, Edinburgh
• Role of Breast Care Nurse	Gill Oliver, Clatterbridge
• Management of neuropathic pain	Carol Davis, Southampton
• Role of occupational therapies	Gloria Luke, Edinburgh
• Management of lymphoedema	Jackie Todd, British Lymphology Interest Group
• Role of specialist surgical intervention	Rolfe Birch, Royal National Orthopaedic, Stanmore
• Role of pain clinic	Frank Kurer, National Hospital for Neurology

These papers were used to inform the work of the Committee. Draft Guidelines were completed on 31 December 1994 for wide circulation before presentation to the Board of the Faculty of Clinical Oncology of the Royal College of Radiologists on 3 February 1995.

4 Radiation Induced Brachial Plexopathy (RIBP)

4.1 Risks and benefits of postoperative radiotherapy for breast cancer

The committee recognises that there is a difficult balance to be struck between the benefits of postoperative radiotherapy in reducing the risks of recurrence and death and the risks of serious morbidity. A relatively high dose of radiation is necessary to sterilise microscopic deposits of breast cancer. Survival may be prolonged by postoperative radiotherapy in selected patients. However, at these levels of dose, there is a relatively steep increase in the risk of complications. The price of reducing dose in order to reduce the risk of major morbidity is an increase in the risk of loco-regional recurrence and possibly cancer related plexopathy.

It is anticipated that the peak incidence of RIBP in the UK has been reached, possibly related to changes in technique over the late 70s and early 80s, but this is only conjecture and will be examined by the formal audit being conducted by Dr Bates and Dr Evans for the Royal College of Radiologists; however, it is also possible that the trend away from supraclavicular fossa and axillary radiotherapy could lead to more cancer related plexopathy. In view of the uncertainty as to which patients benefit from nodal radiotherapy, it is essential that treatment options are discussed carefully with appropriate specialists.

4.2 How is it caused?

In a minority of patients, supraclavicular and/or axillary irradiation may cause oedema and fibrous tissue to constrict the brachial plexus. Substantial loss of myelin occurs with disappearance of the axis cylinders. The neurolemmal sheath itself undergoes varying degrees of fibrous thickening. Hyalinisation and obliteration of blood vessels causes further ischaemia of nerve fibres. The precise mechanisms of damage are still incompletely understood.

4.3 Genetic factors

More recently it has become recognised that individual variations in radiosensitivity to the same total dose and fractionation may be, in part, genetically determined. It has been estimated that up to 20% of patients may be heterozygous for the ataxia-telangiectasia gene which confers substantial enhancement in radiation reactions. This may account for the abnormally intense axillary fibrosis following post operative radiotherapy in some patients. However, at the time of writing this report, there is no reliable test to determine whether an individual is heterozygous for the ataxia-telangiectasia gene or not and other genes may be equally important. While this is a promising area of research, there is no evidence that genetic factors are responsible for the injuries reported by RAGE.

4.4 How frequent is RIBP?

Reports of the incidence of RIBP among women who have undergone postoperative axillary irradiation vary widely. This probably reflects differing criteria for the diagnosis of RIBP and the range of dose and fractionation schedules described in the literature. However, it is a rare complication probably affecting less than 1 % of treated patients. Its rarity means that a general practitioner is unlikely to see a single case during his or her professional lifetime. Similarly, many health care professionals involved in the treatment of breast cancer may be unfamiliar with the clinical features of RIBP.

4.5 How does RIBP present?

The most common presenting symptoms of RIBP are:

- Tingling and numbness of the thumb and forefinger.
- Wasting and weakness of the small muscles of the hand.
- Persistent pain in the shoulder region.

These symptoms appear from 6 months to over 20 years after treatment with the most commonly reported incidence between the 2nd and the 5th year after radiotherapy. It should be emphasised that such symptoms may be caused by a variety of unrelated conditions and, if related to cancer and its treatment, are more likely to be due to recurrent cancer than RIBP.

4.6 How does RIBP evolve?

Typically, a patient will present with numbness of the fingers. Wasting of the small muscles of the hand will follow within months or years. Pain will follow a variable course: characteristically it follows the distribution of nerves supplied by C5 and C6, although it may involve the whole brachial plexus; the features of the pain vary not only in different individuals but also within the same individuals at different times. Such neuropathic pain is notoriously difficult to manage. Between one third and two thirds of patients with RIBP will develop progressive loss of function of the hand and arm over a period of months or years. In a minority, progression may arrest without significant loss of function. As paralysis becomes complete the severity of pain may recede but in other cases persistent causalgic pain remains.

There is a variable incidence of other associated problems including bone necrosis/fracture, lymphoedema and circulation problems. Persistent pain and increasing disability may result in clinical depression and non-specific stress-related illness.

4.7 How is RIBP diagnosed?

Diagnosis may involve the following and their teams:

- Consultant oncologist.
- Breast care nurse.
- Radiologist.
- Neurologist.
- Neurophysiologist.
- Breast surgeon.

RIBP is a diagnosis of exclusion based on the demonstration of a brachial plexopathy in an irradiated site in the absence of other causes, in particular recurrent cancer.

At the time of presenting symptoms and signs it is usually (but not always) possible to confirm a brachial plexopathy, but there are no completely reliable criteria for distinguishing the cause to be radiation rather than recurrent cancer.

Diagnosis rests on:

- Recognition of the significance of the common presenting symptoms
- Competent history and physical examination to identify a neurological deficit and to detect obvious recurrent cancer. This may require assessment by a neurologist as well as clinical oncologist
- Investigations
  - Chest x-ray, cervical spine x-ray.
  - CT/MRI axilla SCF and cervical spine.
  - Biopsy of suspicious areas (preferably under CT control).
  - Neurophysiological tests: nerve conduction and needle studies to identify a lesion in the brachial plexus.
  - Screen for metastic disease: liver ultrasound, bone scan.

The committee proposes the consultant oncologist as best placed to recognise the significance of symptoms and coordinate diagnosis. There was, however, debate among the members of the committee and outside experts consulted as to the appropriate sequence of investigation. Some recommended CT and MRI before neurophysiological tests; others that referral to a neurologist was essential before proceeding to either MRI or neurophysiological studies; others that it would be within the competence of a clinical oncologist to

coordinate all these investigations. Much depends on local expertise and the committee recommends that a local coordinating clinician makes appropriate recommendations; however, this committee would expect that, in the face of persistent symptoms (more than 3 months) and/or objective signs suggesting a brachial plexus neuropathy, patients should have at least:

- CT/MRI scan axilla, supraclavicular fossa (with biopsy under CT control of suspicious areas).
- Neurophysiological studies (nerve conduction and needle studies).

A diagnosis of cancer related plexopathy is suggested by:

- Rapid progression of weakness (particularly involving muscles supplied by *lower* plexus).
- Abnormal supraclavicular/axillary nodes.
- Evidence of metastatic disease elsewhere.
- Horner's syndrome.

Initial absence of these does not exclude the possibility of tumour, as demonstrable cancer has been reported many years after initial symptoms. Abnormal masses should be biopsied, ideally under local anaesthetic, but open exploration may be required. Even then negative findings do not completely exclude cancer.

Plexopathy related to cancer may respond to systemic chemotherapy and/or a second course of radiotherapy; in the presence of rapidly progressive weakness and a negative biopsy patients may consider a trial of chemotherapy in combination with high dose steroids.

4.8 Is there treatment for RIBP?

Surgery

Operations have been described to decompress the brachial plexus and revascularise nerves and surrounding tissues, but there is no treatment which will reliably reverse or change the natural history of RIBP. In general, the most successful results will be obtained with a team of a surgeon with skills in the management of brachial plexus injury (generally an orthopaedic or neurosurgeon) and a vascular and/or reconstructive surgeon used to placing vascularised flaps within heavily irradiated tissues.

The success rates vary both in the literature and amongst reports from individual RAGE members who have undergone surgery, some have noted improvement of motor function and others improvement of pain; however, others have reported deterioration as a result of such surgery. It is possible such surgery may delay vascular insufficiency and avoid progression to complete loss of motor function in selected cases. In general, most value is obtained within 12 months of presenting symptoms. Patients with severe vascular problems have eventually required amputation. It should be noted that this is not an effective measure to relieve pain.

Mr R Birch was consulted by this committee and comments that operations are hazardous and difficult and should not be attempted by the occasional surgeon, but that teams with appropriate skills are available in several parts of the UK. The committee feels that further research is required before producing recommendation for the use of such surgery. Mr Birch, who is prepared to be consulted by health care professionals managing cases, feels there is a need for significant investment in those centres dealing with brachial plexus injury of all sorts, if more surgery and/or research is to go forward.

Medication

Thyroxine and salicylates, e.g. phentoxyphylene have been proposed to inhibit development of radiation fibrosis in selected cases. Recently, the antioxidant agent Cu/Zn superoxide dismutase (Lipsod) has been successfully used to reduce fibrosis, in a French study (Delanian et al 1994). Again more research is required before recommendations can be made.

4.9 How should patients with RIBP be managed?

The key to effective management is a collaborative multidisciplinary approach with honest explanation and communication with the patient, as well as all health care professionals involved. It must be acknowledged that RIBP is essentially an incurable condition, as unrealistic expectations reduce the chances of producing useful improvements in quality of life.

In the absence of definitive treatment, management should be directed towards optimising symptom control and function to maintain as good a quality of life as possible. This should be combined with careful surveillance to detect and treat recurrent cancer, particularly in the first two years after presentation.

The committee considered various health care professionals to coordinate the management of patients with RIBP but concluded that a clinical oncologist is the best placed to recognise the condition, to give an honest explanation both of uncertainties and possible prognosis, and to recognise and treat recurrent cancer.

The committee would expect a coordinating consultant oncologist in each centre to liaise with the following health care professionals and teams in the management of such patients:

- Anaesthetist and psychologist/psychiatrist, as part of pain clinic.
- Breast Care Nurse.
- GP and District Nurse.
- Lymphoedema clinic.
- Occupational therapist.
- Palliative care clinic.
- Physiotherapist.

In addition, a range of complementary therapists (aromatherapists, masseurs, acupuncturists, reflexologists) have been helpful to RAGE members, particularly for those who have been recognised late and have had little or no psychological support. The committee feels more research is needed both in the contribution of complementary therapies and the management of those patients with multiple problems related to axillary tunnel damage, but is not able to make specific recommendations at present.

The key elements of management include:

- Information and explanation to empower patients to help themselves to cope with the condition.
- Systematic management of pain. In view of the emphasis placed by RAGE on this detailed guidelines are included in Appendix IV.
- Assistance with the functions of daily living, in particular access to the recommended aids listed in Appendix V.
- Psychological support including access to a nurse counsellor, information on voluntary organisations and self help groups and regular evaluation for clinical depression.
- Regular surveillance to detect and treat recurrent cancer, particularly in the first 2 years.

The committee recommends that one oncologist in every cancer unit and cancer centre is responsible for identifying and briefing each member of the team to allow coordinated care, following the guidelines in pain management documented in Appendix IV and in provision of aids noted in Appendix V.

The committee has identified a provisional list of named oncologists in every radiotherapy treatment centre in the UK. Ninety per cent of these have access to occupational therapy, physiotherapy, pain clinic,

breast care nurse, lymphoedema clinic, palliative care clinic and complementary therapy.

The committee proposes that the audit of breast cancer treatment includes key symptoms suspicious of brachial plexopathy in order to facilitate future follow up and management of such cases.

4.10 Surveillance

The committee recommends that all those patients with a provisional diagnosis of RIBP are followed by a clinical oncologist at least three-monthly for two years to evaluate:

- Symptoms.
- Function.
- Evidence of recurrent cancer.
- Evidence of clinical depression.
- Other complications, e.g.lymphoedema; pathological fractures; vascular insufficiency

Thereafter they should be seen 6-12 monthly indefinitely depending on their symptoms.

If problems arise in between, the GP is an important point of contact; however, given the rarity of RIBP it is not a condition that they would readily recognise and patients should also be able to have access to a key nurse, ideally a breast care nurse, but failing that, an identified community Macmillan (palliative care) nurse to facilitate speedy referral for re-evaluation.

4.11 Safety net

The committee recognises that, in some cases involving suspected iatrogenic damage, relationships break down with the treating oncologist, in which case it proposes that the breast care nurse should act as key worker to facilitate discussion with the treating oncologist and allow referral to an alternative oncologist in the same centre or the identified regional specialist.

The committee has identified a directory of oncologists in each cancer centre and cancer unit (Appendix VI (i)), and the services to which they have access. It proposes that this information be made available to all breast care nurses through their regional coordinators and, ideally, also to voluntary groups.

The committee proposes that further education of breast care nurses in identification and management of RIBP and associated problems is included in their training, possibly with the addition of regional seminars under the auspices of CRMF. If a patient has no breast care nurse, advice should be available from regional breast care nurse coordinators. The committee has identified a list of these (Appendix VII (ii)).

The committee recognises that many health care professionals will not have seen a case of RIBP. It has not been possible within the time frame and resources of this committee to identify all those with expertise in each discipline but, as a step in the right direction, a group of specialists, including an experienced occupational therapist, physiotherapist, anaesthetist, neurologist, specialist surgeon, neurosurgeon, orthopaedic surgeon, radiologist, palliative care doctor, all of whom have advised the committee, have indicated that they are willing to act in an advisory capacity to their colleagues faced with such cases (Appendix VI (iii)). A more expanded directory will be prepared, if funds become available.

An unacceptable burden is currently falling on RAGE committee members and the committee proposes that written information for patients is produced by a collaboration between BACUP, CancerLink and Breast Cancer Care and a more extended directory of advisory services made available.

In addition the Committee has liaised with BACUP and CancerLink to facilitate formal counseling and help to RAGE committee members in their work in supporting patients. This committee feels that the supportive as well as the campaigning role of RAGE should be acknowledged.

5 Summary of guidelines

5.1 Information after radiotherapy

While the chance of axillary tunnel damage is small, all those who have received radiotherapy to the supraclavicular fossa and/or axilla should be given information to allow them to recognise and report significant symptoms to obtain rapid expert assessment and management

When patients complete radiotherapy symptoms to watch for should be given to both patients and GP. Included in this should be the information that persistent tingling of the fingers, particularly associated with shoulder pain or weakness of the hand, should result in urgent assessment by the treating oncologist, as it could *rarely* be an early symptom of recurrent cancer, or a complication related to surgery or radiotherapy.

5.2 Diagnosis

Diagnosis of RIBP rests on demonstrating brachial plexopathy in an irradiated site in the absence of other causes, particularly recurrent cancer. Even in the absence of a negative biopsy, recurrent cancer cannot be absolutely excluded particularly over the first 2 years from presentation. Key elements of diagnosis include:

- Recognition of presenting symptoms.
- Physical examination.
- X-ray chest and cervical spine.
- CT/MRI scan of supraclavicular fossa, axilla and cervical spine.
- Biopsy of suspicious lesions.
- Electrophysiological studies (including both nerve conduction studies and needle studies) to localise lesion in the brachial plexus.

5.3 Surveillance

Patients with a provisional diagnosis of RIBP should be followed three-monthly for 2 years and thereafter 6-12 monthly depending on symptoms

5.4 Management

Management involves a multidisciplinary team coordinated by a clinical oncologist designated in every cancer centre and cancer unit. The coordinating consultant oncologist is responsible for liaising with the following to make sure they are aware of protocols:

- Breast care nurse.
- Breast surgeon.
- GP and District Nurse.
- Occupational therapist.
- Pain clinic (anaesthetist,psychologist/psychiatrist).
- Palliative care clinic.
- Physiotherapist. and, if possible,
- Complementary therapists.

Key elements of management include:

- Information and explanation to empower patients to help themselves
- Systematic management of pain (Appendix IV).
- Assistance with functions of daily living (Appendix V).
- Psychological support including access to voluntary groups
- Regular surveillance to detect and treat cancer.

5.5 Safety net

Where patients have problems either in gaining access to a diagnosis or treatment, a breast care nurse should be able to facilitate this. Information and advice as to management contained in a fact sheet and directory of services is proposed to be circulated to all breast care nurses and voluntary organisations. This information will be available to patients although experts will only be able to give advice to fellow health care professionals.

Appendix 1
Consultation with Radiation Action Group Exposure (RAGE)

Appendix 1 (i)
Consequences and symptoms of radiation damage as documented by RAGE

Amputation of arm at elbow or shoulder

Spontaneous fractures of bone which heal slowly or not at all. Bones affected are ribs, arm, collar bone, shoulder blade. Vertebrae and sternum "crumbling".

Brachial Plexus nerve injury. Affects hand, fingers, arm, shoulder, neck. Intense tingling pins and needles in all or any affected area. Numbness of skin. Paralysis of part or all of affected area. Very poor circulation in affected area - frostbite sensation. Hardness in shoulder area. Stiffness of movement. Severe cramping and spasm. Locking of joints.

Severe unrelievable pain in all or any affected area. Strong opiates prescribed in many cases. Various pain regimes, e.g. nerve blocks, tens machines, acupuncture, cordotomy, steroid injection, various drug regimes not effective.

Lymphoedema. Swelling of arm on affected side often accompanied by intense pain and restricted movement. Can lead to infection and cellulitis.

Respiratory problems caused by lung damage. Condition often referred to is "pneumonitis". Breathlessness and much distress. Some cases treated for "life" by steroids, nebulisers. Similar damage to trachea and bronchii and chest wall. Death has occurred of this complication.

Skin conditions which are difficult to treat and can become chronic. Burns, sores, severe rashes akin to shingles. Plastic surgery needed in some cases, or mastectomy (following lumpectomy). Inflammation and intense sensitivity. Bad scarring, scleroderma.

Digestive problems. Burning of oesophagus leading to scarring. Symptoms akin to hiatus hernia, food causes burning and sticking. Very painful and distressing. "Lump" in throat. Teeth affected on treated side.

Heart problems. Blood vessels affected, bypass operations.

A miscellany of less common problems, e.g. underfunctioning of thyroid, general arthritic conditions.

Appendix I (ii)
Experience of RAGE members

Diagnosis:

1 Not admitted.
2 Not admitted, no other diagnosis suggested.
3 Suspected by patient, other diagnoses suggested; e.g.: frozen shoulder; wear and tear on vertabrae (spondylitis); arthritic changes; tennis or golf elbow; problems relating to age; strain; carpal tunnel syndrome; bad posture.

BPI admitted as a result of:

1 Physical examination.
2 X-ray.
3 CAT scan.
4 MRI scan.
5 Nerve conduction tests.
6 Biopsy.

Surgical intervention:

1 De-compression operations, varying types.
2 Skin and tissue graft.
3 Removal bone fragments.
4 Amputation.
5 Vertebral fusion.
6 Nerve severence (cordotomy).
7 Bone graft.
8 Blood vessel shunt.

Pain relief, physical:

1 Injected nerve blocks.
2 TENS machine.
3 Acupuncture.

Pain relief, drugs:

1 Aspirin, paracetomol.
2 NSAIDs.
3 Anti-depressants.
4 Steroids.
5 Muscle relaxants.
6 Opiates.

General therapies:

1 Physiotherapy.
2 Massage.
3 Hydrotherapy.

Alternative and complementary therapies:

Alexander technique; amino acid supplements; aromatherapy; B12 injections; Chinese medicine; chiropractic; healing; herbal remedies; homeopathy; hyperbaric oxygen; hypnotherapy; kinesiology; meditation; negative ions; osteopathy and cranial osteopathy; reflexology; shiatsu;; vitamin and mineral supplements; yoga

Appendix I (iii)
Experience of RAGE members

a) Issues of particular importance raised by RAGE committee members.

1 Early diagnosis.

2 Self referral by patients if necessary.

3 Access to self help groups, possibly via GPs etc.

4 Avoidance of 'being shunted from pillar to post'.

5 Education for health care workers about problems related to radiation damage by a symposium or seminar; 'mandatory standards' rather than guidelines should be the aim.

6 Prevention of isolation of sufferers.

7 Need for information of all possible approaches to coping with radiation damage, possibly a library of information.

8 Research into all means of help.

9 Overcoming the conspiracy by hospitals to deny problems and to try and isolate patients.

10 Need for information as to what to expect in the future.

b] Summary of issues to be addressed (after discussion with RAGE).

1 Problem to be acknowledged and explained.

2 Who should be responsible for dealing with the problem.

3 How to obtain diagnosis.

4 Symptoms need to be addressed (as per RAGE list)

5 Education and training of primary care workers as well as cancer doctors.

6 Provision not just of guidelines, but of mandatory standards linking in with what services already exist.

7 Pooling of all information about research in this field in a form accessible to patients.

8 Easy access to appropriate prosthesis.

9 Access to appropriate physiotherapy.

10 Recognition of need for holistic approach.

11 Difficulties of often disabled and ill people in reaching places where treatment is available and the financial implications of this.

12 Access to self help groups.

13 Continuous follow up.

14 Access to written information.

15 Clarification of the likely progression of problems.

Appendix i (iv)
RAGE's analysis of the replies to their questionnaire

RAGE sent out 640 questionnaires and had 180 replies (28 %); this is an analysis of the replies.

1. *Has it been admitted that your symptoms are caused by radiotherapy?*

   60 % have been diagnosed as having radiotherapy damage, 40 % have not.

2. *Are you on medication for pain relief? If so, what medication are you using? Is it effective?*

   70 % are on some form of medication, 30 % do not take medication. Medication range from opiates, anti-depressants and steroids to aspirin and paracetamol. Of those taking medication, 50 % get no relief at all, 10 % sometimes get some relief, 40 % found their medication effective (these tended to be the women on opiates).

3. *Have you had surgery to relieve symptoms?*

   Only 10 % have had any form of surgery (mostly BP decompression).

4. *Have you attended a pain clinic? Was it helpful?*

   25 % have attended a pain clinic; 90 % found it helpful.

5. *Have you received physiotherapy? Was it on the NHS? Was it effective?*

   60 % have received physiotherapy; 90 % were treated on the NHS; only 20 % found it effective.

6. *Have you received acupuncture? Was it on the NHS? Was it effective?*

   25 % have received acupuncture; approximately half received it on the NHS; only 10 % found it effective.

9. *Have you received any other therapy?*

   The most popular alternative therapies were reflexology and massage.

10. *Have you received any psychological support?*

    Only 5 % had received psychological support: of these 78 % said it was helpful.

11. *Do you use any aids?*

    50 % use some form of aid.

12. *Overall, how do you consider you have been treated?*

    50 % feel they have been treated indifferently, 25 % badly and 25 % well.

13. *What would you welcome now in the way of treatment?*

    Ranking of answers:

Expert diagnosis with honest prognosis	1st
Effective pain control	2nd
Alternative therapies	3rd
Psychological counseling	4th
Surgery	5th

Appendix 2
Literature Review

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Appendix 3
Organisations approached

Association for Palliative Medicine
BACUP
BASO
BLIG
Breast Cancer Care
CancerLink
College of Health
CRMF
Marie Curie Cancer Care
RAGE
Royal College of Nursing
Royal College of Radiologists
Royal Homeopathic Hospital

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Appendix 4
Symptomatic Management Of Neuropathic Pain

Prepared by Dr Carol Davis, Senior Lecturer in Palliative Medicine, Countess Mountbatten House, Southampton.

Introduction

Radiotherapy for breast cancer can cause immediate effects such as desquamation of skin and acute neuropathic pain which are usually self-limiting. Post-breast surgery and mastectomy syndromes are common in up to 15 % of patients, some of whom also present with neurological damage, particularly to the intercostal-brachial nerve.

Classical long-term sequalae of radiotherapy can develop between 6 months and over 20 years from treatment. They are caused by damage to the brachial plexus, lymphatics, vasculature and bones and are characterised by progressive functional loss with or without pain and lymphoedema. Tumour recurrence can also account for progressive brachial plexus damage but is more common in the lower nerve roots C8 to T1, which are relatively protected from radiation damage by the clavicle, in contrast to radiation damage which is most common in the upper roots C5/6.

Clinical Features And General Approach To Management

Neuropathic pain implies pain in the distribution of a nerve, secondary to functional or pathological change in the nerve. In the context of post-radiation pain in patients treated for breast cancer, it is caused by damage to the brachial plexus (brachial plexopathy).

Neuropathic pain is recognised as a difficult pain to treat. Ideally, the first step in symptomatic management is to establish the diagnosis but this is not necessarily clearcut in patients with brachial plexopathy and cancer (Kori et al 1981).

The features of the pain vary not only in different individuals but also within the same individual at different times: the pain may be constant or intermittent and occurs in the distribution of affected nerves.

Common descriptors of neuropathic pain: burning, shooting, pins and needles, tingling, toothache, numbness, cramp, stiffness, frostbite, tightness.

The key to diagnosis lies in a thorough clinical history and examination which may need to be supplemented by appropriate investigations such as CT scan and MRI. Investigations must be directed at establishing whether the symptom is a sign of treatment-related nerve damage or recurrent disease.

Symptomatic treatment should not be delayed and can be commenced whilst investigations are underway. Unless active tumour is demonstrated, management should be aimed at optimising symptom control and function, thus maintaining as good a quality of life as possible. A collaborative and *multi-disciplinary* approach is required. Open and honest *explanation* is essential as is good communication with *all* involved. Appropriate information must be available for both patients and health care professionals. Many patients will have been cured of breast cancer and the aim of treatment should be pain relief that is as complete and long-lasting as possible. It is important that side-effects of the treatment are kept to a minimum and that they do not increase the patient's disability. The least toxic treatments should be tried first.

Symptomatic Management

This includes:

1. Pharmacological and non-pharmacological strategies.
2. Psychological approaches.
3. Help with activities of daily living.
4. Interventional techniques.

1. Pharmacological And Non-Pharmacological Strategies

Neuropathic pain is relatively insensitive to conventional analgesics including non-steroidal anti-inflammatory drugs (NSAIDs) and both weak and strong opioids. Radiotherapy-induced neuropathic pain in the upper limb may *co-exist* with other pains including *bone pain* and *visceral/soft tissue pain* which are usually sensitive to these agents. Pharmacological treatment must therefore be directed at each component of the pain.

Adjuvant analgesics

Tricyclic anti-depressants, such as amitriptyline, dothiepin and clomipramine should be used as first-line pharmacological therapy. Amitriptyline is the most likely to cause side-effects but is, like the others, very effective treatment for neuropathic pain. The dose should be slowly titrated upwards. The sedative effects of some anti-depressants can be utilised to improve sleep. Pain relief is independent of the effects of the drug on depression but, if the patient is clinically depressed, there is no doubt that relief of depression will improve the patient's perception of the pain.

Anti-convulsants are usually used as second-line pharmacology treatment and can be particularly useful in cases with paroxysmal, shooting pain. Some clinicians replace anti-depressants with one of this class of drugs whilst others use them together. These strategies have not been compared in a clinical trial in patients with neuropathic pain of any aetiology. Carbamazepine and sodium valproate are most commonly used; if one anti-convulsant does not work even after dose-escalation, then there is possibly less likelihood of success with another.

Refractory pain can be treated with *anti-arrhythmic* drugs (flecainide or mexilitine) but caution is necessary in patients in whom cardiac status may be compromised by previous radiotherapy or ischaemic heart disease. Some centres only prescribe such treatment after a successful intravenous lignocaine challenge.

The use of adjuvant analgesics is well reviewed elsewhere (Charlton 1993, Portenoy 1993).

Baclofen can be helpful, particularly if the pain is of mixed aetiology and there is a post-surgical element to the pain, for example intercostal-brachial nerve damage.

Corticosteroids can be useful in the management of neuropathic pain, but should be used in the setting of radiotherapy induced neuropathic pain with *extreme caution* because of long-term toxicity.

There is some evidence that the application of *topical NSAID's, local anaesthetics and capsaicin* can relieve neuropathic pain through a direct effect on cutaneous, sensory nerve endings.

There is increasing clinical and laboratory evidence that *NMDA receptor antagonists*, such as ketamine, can relieve neuropathic pain but toxicity can be severe and dose-limiting. Agents available to date have to be administered parenterally and are currently undergoing further evaluation. Others are being developed.

Conventional analgesics

The insensitivity of neuropathic pain to conventional analgesics, particularly opioids, is the subject of considerable debate. There is little doubt that this type of pain is relatively insensitive to opioids but some believe that high doses of morphine or standard doses of alternative opioid analgesics such as methadone can bring about symptom relief. *A short trial of dihydrocodeine, morphine or methadone is justified in patients who have failed to respond* to other pharmacological strategies, since long term benefit can be obtained in a proportion of such patients.

Non-pharmacological strategies

The local application of *heat or cold* is often helpful though cumbersome. Neuropathic pain is sometimes eased by gentle rubbing and *massage* with or without essential oils which should not be used if the skin is broken. Benefit from these strategies is a useful predictor of success with TENS or acupuncture.

Transcutaneous electrical nerve stimulation (TENS) is a simple non-invasive technique which can be particularly helpful for neuropathic pain (Thompson and Filshie 1993). It should be used early in the course of treatment either before or alongside a tricyclic anti-depressant. Electrodes are frequently sited paravertebrally alongside affected segments (e.g. C5 and 6) with or without peripheral placement either proximal to the painful areas or on trigger points. It is usually necessary to adjust repeatedly the stimulation sites before optimal pain relief is achieved and this technique should not be abandoned before this has been tried. *A minimum trial of three weeks duration*, trying sequential placement sites and varying other parameters including the machine so that continuous, burst and modulated outputs are tried, has been found helpful in patients with avulsion neurological injuries and is recommended.

The *physiotherapist* is often the best person to advise on the use of pain relieving techniques such as heat, ice, TENS and massage as well as to give advice on mobility and functional adaptation. Careful assessment, advice on positioning, skin care, splinting, supportive aids (e.g. slings) and muscle re-education may be necessary where brachial plexus damage has occurred. Progressive graded exercises, including mobilisation and soft tissue stretching exercises may be appropriate to maintain and improve range of movement and minimise the effects of muscle fibrosis following radiotherapy.

Instruction in self-management is important as is prophylactic advice to prevent further complication due to sensation loss and to alert the patient to the signs of early lymphoedema.

Acupuncture can provide relief of neuropathic pain (Thompson and Filshie 1993). It appears to have a sympatholytic effect and can improve functional ability. Symptom relief, if achieved, is cumulative and after three treatments at weekly intervals, the treatment intervals can be increased (Filshie, personal communcation).

The role of *complementary therapies* in the mangement of patients with brachial plexopathy requires medical evaluation. It is essential that the practitioner is aware of the nature and cause of the symptoms. Healing, gentle massage and aromatherapy may be comforting and are unlikely to cause harm.

2. Psychological approaches

Chronic pain of any cause is often associated with psychological morbidity. A wide range of emotions including anger and bitterness are normal reactions to this situation and are often more intense if the problem has been induced by treatment. These emotions can become pathological and contribute to anxiety and depression.

There is evidence that a variety of strategies can be employed to prevent psychological morbidity; these include giving appropriate information and advice, acknowledging distress and openly discussing the likely cause of the pain and the possible treatment options. Some strategies can be used to limit pre-existing psychological morbidity. A proprotion of patients with radiotherapy-induced brachial plexopathy will require specialist psychological and/or psychiatric support.

3. Activities Of Daily Living

The patient should have early access to a hospital-based or a community-based occupational therapy service. An individual and full physical, functional, psychological and social assessment is essential. Following this, advice on appropriate coping strategies and the use of practical equipment (Appendix V), if necessary, can be given. Adaptations to the home and car may be required. The patient's needs may change with time and so follow-up visits should be arranged as necessary.

4. Interventional Techniques

Nerve blocks

The plasticity of the nervous system is such that so-called "permanent" nerve blocks may only last for days, weeks or months but side-effects may be permanent and unacceptable for some patients. Such blocks should be reserved for highly selected patients treated in specialised centres. Regional guanethidine and stellate ganglion blocks are the most commonly performed.

Neurosurgical procedures

In a small proportion of patients, neurosurgical intervention will be required. The most appropriate procedure is determined not only by the patient's symptoms but also by the results of investigations delineating the degree of nerve damage and the chances of long-term success. Dorsal root entry zone ablation (DREZ) is one such operation; M. Powell at the National Hospital will offer advice on this.

Organisational Issues

Each patient will have individual needs but patients should have access, through their general practitioner to a clinical oncologist (see the Summary of the Guidelines p.???). Good communication is essential both between team members and between the team, the patient and their family.

Research And Training Issues

Good clinical practice should be research-based whenever possible. There is an urgent need for clinical trials and relevant laboratory studies addressing the management of patients with brachial plexopathy after radiotherapy. In addition, within the core curriculae for students and systems of continuing education for trained personnel, it is essential that certain issues are covered in detail, i.e. communication skills, including listening skills, assessment of pain, management of pain, holistic approach to patient care.

Conclusions

The management of patients with radiotherapy-induced brachial plexopathy requires an open-minded, multidisciplinary, patient centred approach. A combination of pharmacological and non-pharmacological strategies will be required and should be used logically. Adequate therapeutic trials are essential. First-line treatment should comprise TENS with or without a tricyclic antidepressant. Early access to physiotherapy and occupational therapy services and to psychological support when necessary is vital. The aim of management should always be optimisation of symptom control and function so that the patient can enjoy as good a quality of life as possible.

References

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Kori SH, Foley KM, Posner JB. Brachial plexus lesions in patients with cancer: 100 cases. Neurology 1981; 31: 45-50.

Maguire P. ABC of breast diseases: psychological aspects. British Medical Journal 1994; 309: 1649-1652.

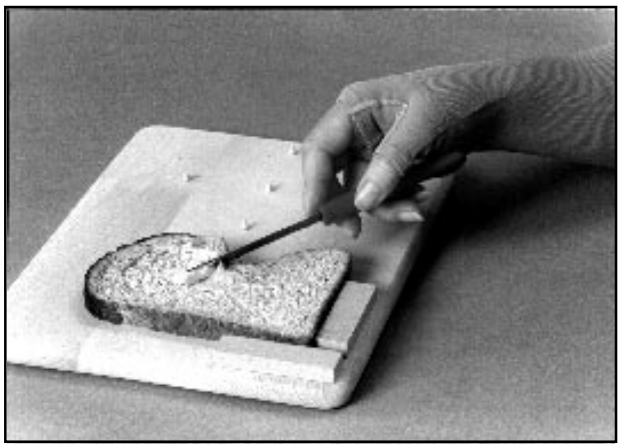
Portenoy R. Adjuvant analgesics in pain management. In: Oxford Textbook of Palliative Medicine, Ed: Doyle D, Hanks GWC, Macdonald N; 1993: 187-203, Oxford Medical Publications

Thompson JW and Filshie J. Transcutaneous electrical nerve stimulation (TENS) and acupuncture. In: Oxford Textbook of Palliative Medicine, Ed: Doyle D, Hanks GWC, Macdonald N; 1993: 229-244, Oxford Medical Publications.

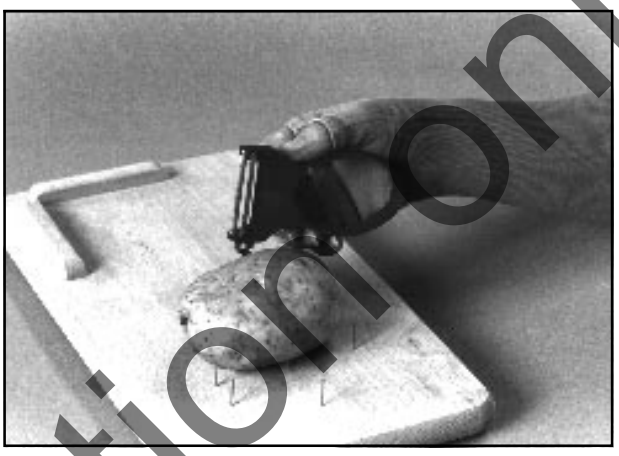
Appendix 5
Occupational Aids

These aids have been recommended by the Occupational Therapy Department of Western General Hospital, Edinburgh; they are available from specialist suppliers.

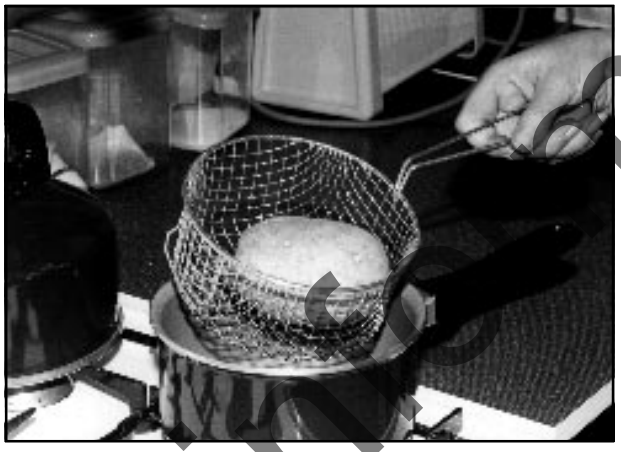
1. One-handed bread and vegetable board (demonstrating spreading bread).



2. One-handed bread and vegetable board (demonstrating peeling potatoes).



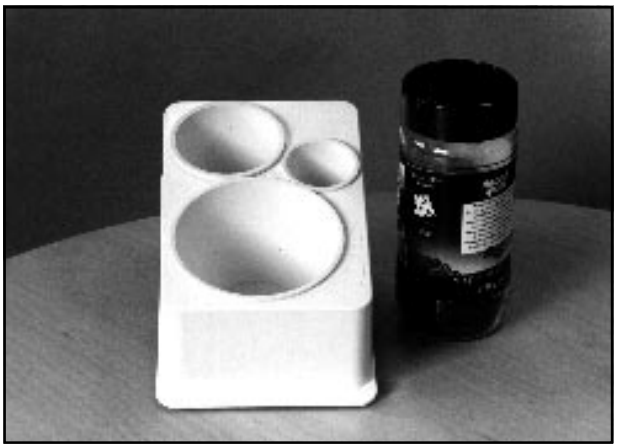
3. One-handed vegetable basket for straining cooked vegetables.



4. Plate guard and one-handed fork with blade for cutting.

5. Electric can opener for one-handed use.

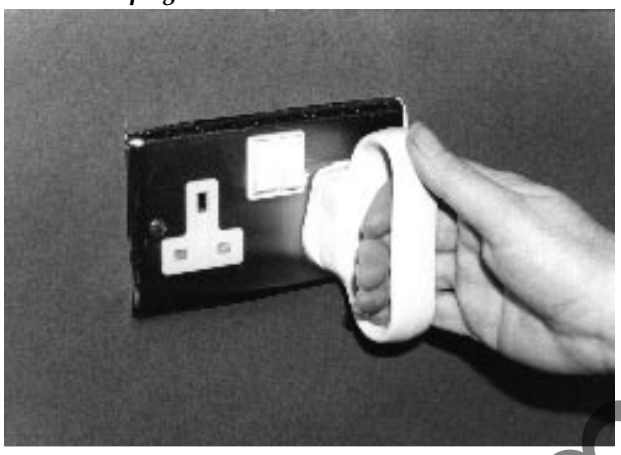
6. "Spill Not" one-handed bottle/jar holder.



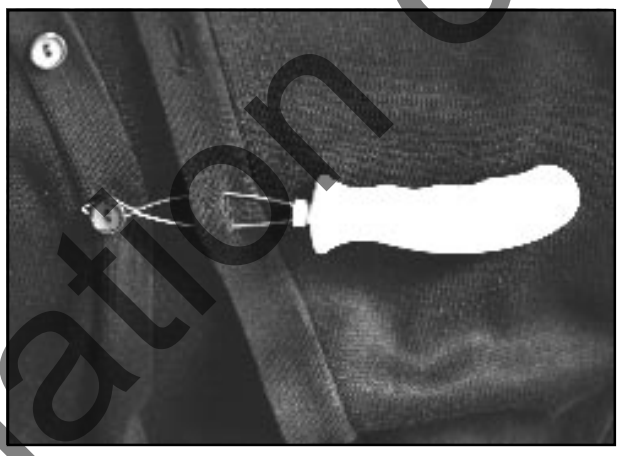
7. "Spill Not" and rubber twister for unscrewing lids of bottles and jars.

8. Multipurpose clamp – good leverage for small items, turning knobs on radios etc.

9. Electric plug with handle.

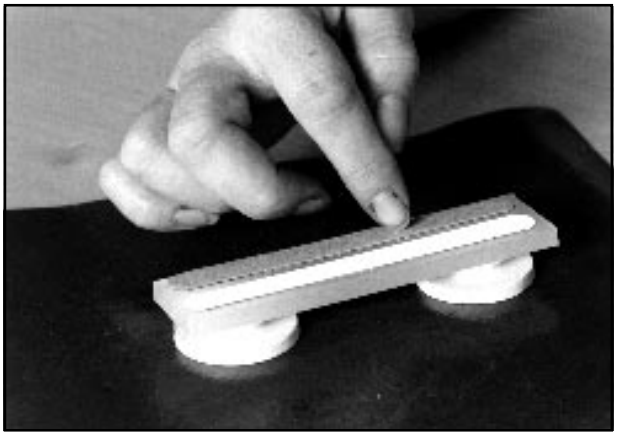


10. One-handed button hook.

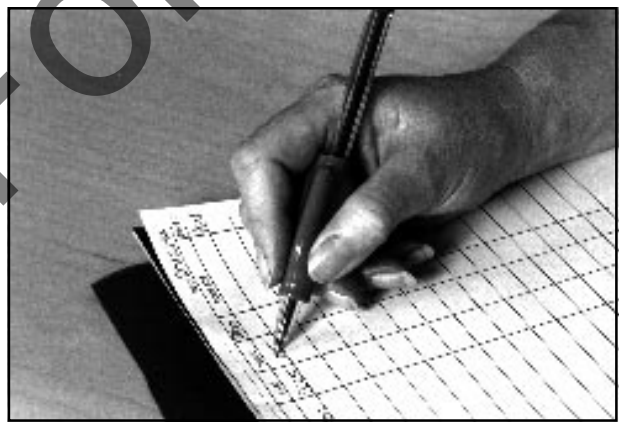


11. One-handed suction nail brush.

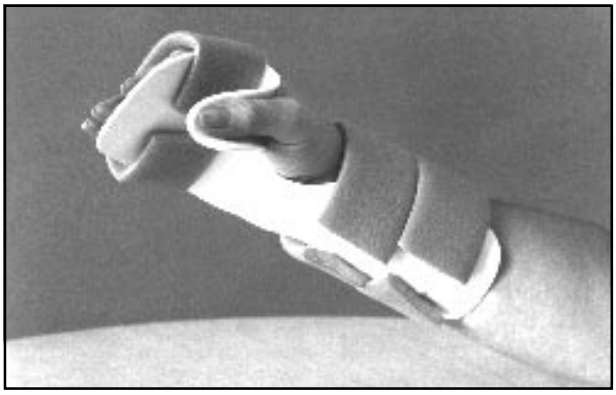
12. One-handed suction nail file.



13. Plastic pen/pencil grip.



14. Night resting splint to prevent flexion contractures, individually made to measure.



Appendix 6
Directories

One oncologist is to be designated in each radiotherapy unit to co-ordinate services. This oncologist will:

1. Be responsible for identifying and circulating guidelines to:

   Breast care nurse

   Breast surgeon

   Occupational therapist

   Physiotherapist

   Pain clinic (anaesthetist, psychologist/psychiatrist)

   Palliative care clinic

   and, if possible, complementary therapists.

2. Take referrals where relationships broken down, or no oncologist has been consulted so far.

A list has been drawn up together with local facilities available to them. This list is *provisional* and local discussion may result in changes which will be forwarded to the Clinical Audit Unit of the Royal College of Radiologists for dissemination.

Where there are problems gaining access to a clinical oncologist, GPs and district nurses are extremely important points of contact, but may not be familiar with RIBP, thus a breast care nurse may be able to facilitate. Many patients do not currently have a breast care nurse and a list of regional advisers are included who can put patients in contact with a local nurse. Similarly BLIG representatives may offer advice as to where to seek help concerning lymphoedema.

Health care professionals willing to act as sources of expertise

Local lists have been provided, given the priority expressed by RAGE for the provision of local services and not to be 'pushed from pillar to post' but, as many health care professionals will not have seen a case of RIBP, an informal list of specialists has been drawn up to give advice to local colleagues on aspects mentioned in the Guidelines. This is *not* a list of national experts, but rather of professionals familiar with the management of RIBP, who have advised the committee and who are prepared to provide informal advice to their colleagues. If funds become available a more formal list will be prepared.

Anaesthetist	Dr Jackie Filshie, Royal Marsden Hospital (inc. acupuncture)
BLIG	Jackie Todd, Ardenlea Marie Curie Centre
Neurology	Dr Robin Grant, Western General Hospital, Edinburgh
Neurophysiology	Dr AAA Bajalan, Hull Royal Infirmary Dr AA da Costa, St James's Hospital, Leeds Dr Peter Fawcett, Hon. Sec. ABCN, Newcastle General Hospital Dr C Fisher, Western General Hospital, Edinburgh Dr A forster, Dundee Royal Infirmary Dr MH Morgan, Frenchay Hospital, Bristol Dr K Nagendran, St Bartholomew's Hospital Dr CP Panayiotopoulos, St Thomas's Hospital Dr C Ponsford, Walsgrave Hospital
Neurosurgery	Dr M Powell, National Hospital for Neurology and Neurosurgery
Occupational therapy	Ms Gloria Luke, Western General Hospital, Edinburgh Ms Jo Bray, Warren Pearl Marie Cure Centre, Solihull
Palliative Care	Dr Carol Davis, The Royal Marsden Dr Ilora Finlay, Marie Curie Cancer Care Centre, S. Glamorgan
Physiotherapy	Ms D Robinson, St Catherine's Hospice, Scarborough
Plastic surgery	Prof R Saunders, Mount Vernon Hospital
Radiology	Dr W Ayoub, Mount Vernon Hospital
Radiotherapy	Prof K Sikora, Hammersmith Hospital Dr E J Maher, Mount Vernon Hospital
Surgery	Mr R Birch, Royal National Orthopaedic Hospital

Provision of care by centre with NHS region/country

(extracted from the COIN database)

Region/Country	Centre	Clinical Oncologist	Breast Care Nurse	Pain Clinic	Pall. Care Physician	Physio.	Occupl. Therapy	Compy. Therapy
Northeast & Yorks	Carlisle	P Dyson	y	y	y	y	y	y
	Cleveland	P R C Dunlop	y	y	y	y	y	y
	Hull	C I Preston	y	y	y	y	y	y
	Leeds	D Ash	y	y	y	y	y	y
	Newcastle	P J D Dawes	y	y	y	y	y	y
Trent	Derby	A Benghiat	y	y	y	y	y	y
	Leicester	F J F Madden	y	y	y	y	y	y
	Lincoln	J M Eremin	y	y	y	y	y	
	Nottingham	D A L Morgan	y	y	y	y	y	y
	Sheffield	K S Dunn	y	y	y	y	y	y
East Anglian & Oxford	Cambridge	T Wheeler	y	y	y	y	y	
	Ipswich	J H Le Vay	y	y	y	y	y	y
	Northampton	A L Houghton	y	y	y	y	y	y
	Norwich	M J Ostrowski	y	y	y	y	y	
	Oxford	A C Jones	y	y	y	y	y	y
	Reading	J M Barrett	y	y	y	y	y	y
N Thames	Barts	P N Plowman	y	y	y	y	y	
	Charing Cross & Westminster	C P Lowdell	y	y	y	y	y	y
	Colchester	D Gamble	y	y	y	y	y	
	Hammersmith	C Vernon	y	y	y	y	y	y
	Middlesex & UCH	M F Spittle	y	y	y	y	y	y
	Mount Vernon	P A Lawton	y	y	y	y	y	y
	North Middlesex	S A Davies	y	y	y	y	y	y
	Oldchurch	M M Quigley	y	y	y	y	y	
	Royal Free	C H Collis	y	y	y	y	y	y
	Royal London	B S Mantell	y	y	y	y	y	
	Southend	C W L Trask	y	y	y	y	y	y
S Thames	Brighton	G Deutsch	y	y	y	y	y	y
	Canterbury	R S Coltart	y	y	y	y	y	y
	Guildford	W F White	y	y	y	y	y	y
	Mid-Kent	M P Snee	y	y	y	y	y	y
	Royal Marsden	J R Yarnold	y	y	y	y	y	y
	S E London	A R Timothy	y	y	y	y	y	y
South West	Bath	G J G Rees	y	y	y	y	y	y
	Bristol	E C Whipp	y	y	y	y	y	y
	Cheltenham	J R Owen	y	y	y	y	y	y
	Exeter & Torbay	A Hong	y	y	y	y	y	y
	Plymouth & Truro	C J Tyrell	y	y	y	y	y	
	Poole	T D Goode	y	y	y	y	y	y
	Portsmouth	P Golding	y	y	y	y	y	
	Southampton	C R Hamilton	y	y	y	y	y	
W Midlands	Birmingham	T N Latief			y	y	y	
	Coventry	D A Jones	y	y	y	y	y	y
	Shrewsbury	R K Agrawal	y	y	y	y	y	y
	Stoke	A M Brunt	y	y	y	y	y	
	Wolverhampton	T J Priestman	y	y		y	y	y
N West	Christie	B Magee	y	y	y	y	y	y
	Clatterbridge	R D Errington	y	y	y	y	y	y
Wales	Swansea	T Joannides	y	y	y	y	y	y
	Velindre	P Barrett-Lee	y	y	y	y	y	y
Scotland	Aberdeen	T K Sarkar	y	y	y	y	y	y
	Dundee	J A Dewar	y	y	y	y	y	y
	Edinburgh	I H Kunkler	y	y	y	y	y	y
	Glasgow	A N Harnett	y	y	y	y	y	
	Inverness	M H Elia	y		y	y	y	
N Ireland	Belfast	P Abram	y	y	y	y	y	y

Regions where BCNN and BLIG representatives have been identified

BCNN is the British Cancer Nurses Network. BLIG is the British Lymphology Interest Group.

Region/Country	BCNN Contacts	BLIG Representatives
Northeast & Yorks	Sandra Horsfield Newcastle General Hospital Newcastle upon Tyne NE4 6BE Barbara Smith Royal Halifax Infirmary Halifax HX1 2YP	Angela Egdell St Oswald's hospice Gosforth NE3 1EE Terry McCroakam 12 Chiltern Drive Ackworth WE7 7DW
Trent	Judith Stewart City Hospital Nottingham NG5 1PB	Sue Crooks 117a London Road Derby DE1 2QS
East Anglian & Oxford	Jenny Beer Norfolk & Norwich Hospital Norwich NR1 3SR Heather Brown Battle Hospital, Reading RG3 1AG	Hazel Charge 351 Mill Road Cambridge CB1 3DF
N Thames	Nora Chute Edgware General Hospital Edgware HA8 0AD Judith Spencer-Knott St Margaret's Hospital Epping CM16 6TN	Sue Lawrence 74 Inverness avenue Enfield EN1 3NU Elizabeth Hirschman Three Chimneys Wallington SG7 6SN
S Thames	Pauline Wilgoose Royal Surrey County Hospital Guildford GU2 5XX Edna Elias Rayne Institute 123 Coldharbour Lane SE5 9NU	Sally Edwards flat 56, New Crane Wharf 8 New Crane Place E1 9TX
South West	Sue Williams Yeovil District Hospital, Yeovil BA21 4AT Mavis Wing Royal South Hants Hospital Southampton SO9 4PE	
W Midlands	Lynne Dodson Dudley Road Hospital Birmingham B17 8QH	
N West	Maureen Bunting Royal Albert Edward Infirmary Wigan WN1 2NN Cathy Alderson Royal Liverpool University Hospital Liverpool L7 8XP	
Wales		Carol Jordan Velindre Hospital Cardiff CF4 7XL Linda Johnson Wrexham Maelor Hospital Wrexham LL13 7TD
Scotland	Gaye McPhail 68 Oakfield Avenue Glasgow G12 8LS	Barbara Lyle Western General Hospital Edinburgh EH4 2XU Jenny Eldret 1 Bishop's Walk Inverness IV3 5SB
N Ireland	Jean Gray Royal Victoria Hospital Belfast BT12 6BA	Jenny Brennan Ulster Hospital Belfast BT16 0RH
Ireland		Ann O'Brien St Vincent's Hospital Dublin 4