

If you have had a concern about a consequence or late effect of your cancer or its treatment?

How did you know what to do/who to see?

- Problems listed – ligament damage in left leg, deafness, memory loss, lymphodema, fatigue, osteoporosis, suppressed immune system.
 - Most people don't know who or where to go and would normally go to their GP.
- Didn't really know who to see, so went to see GP.
- Learnt from my own reading and other survivors, who told me to be more assertive with professors, 99% of whom denied risks.
- Went to Clive Sargent and round and round until lucky enough to meet Prof Mike Hawkins who referred me to Prof Stevens, who allowed me to refer myself to his clinic.
- Unsure – spent lots of time with my GP who tells me he should not have to sort out Consultant's problems.
- GP, knew I was unwell, but couldn't pinpoint it. We went through the late effects list but could not pinpoint a specialist to refer me to. He didn't know what to do. I waited for more symptoms. Five months later Jo Heath sent a recall letter (Hodgkins – BC) which sent me for a mammogram which found the breast cancer.
- Telephone number given with contact details.
- GP/Internet.
- I was told always to see my GP if they had 'symptoms', however vague.
- Went back to see old oncology team who could refer me on.
- Vague symptoms – what to do? Emailed chemo trial co-ordinator who brought my appointment forward.
- Pain in right back and shoulder after radiotherapy. Went to GP, had an x-ray, done.
- Firstly, consultant; secondly, GP; thirdly, clinical nurse.
- Secondaries? What's that? I had no idea, eventually went back to GP. Due to lack of information it was five months before going.
- I went to a health awareness day and had a scan which showed I had osteoporosis – was advised to ask my GP to send me for a body scan.
- Spoke to breast nurse about hot flushes – she organised acupuncture.
- I rang lymphodema support network. I went to GP re vaginal problems. During Consultant's pre-surgery scan, consultant found vaginal adhesions.

How easy was this to make it happen?

- Not easy, had to go back.
- Very difficult to pin-point if from the treatment – quite often told that after-effects not from treatment. Very difficult.
- Very difficult, but once recognised. Not easy; don't listen.
- Had to refer myself due to GP not wanting to, or not allowed to, due to their own boundaries.
- Easy to see GP, but still cannot sort out problem ongoing.
- Impossible through GP system despite his total support and active involvement.
- Easy to make appointment with GP.
- Had to be very assertive to be heard (yet not by nature).
- Rang up at lunchtime and told to come in at 4pm – problem dealt with.
- Internet: easy. GP: very little use.
- Very easy.
- Contact oncologist for cancellation appointment – get advised and support.
- Consultant - Post code lottery.
- It was very easy to do.
- Very easy – organised through the hospice.

How many steps did you go through before you got to the person you needed?

- Two steps.
- Emailed oncologist and self referred – time span?
- GP ended up organising everything that I needed.
- GP referred me to bone pain specialist. This took approx 3 weeks.
- Was told my first appointment was x date, which would have meant missing the 2 and a half referral guideline by weeks. Had to kick up a fuss before being seen and was diagnosed that day.
- 3 – 4 steps.
- 4 steps – Internet – GP – Hospital – GP !
- One step – email.
- Many, multiple.
- Only had to make appointment with my GP.
- Not many – very easy.
- 4 at least.

What worked well?

- Support – once diagnosed, surgery quickly.
- Thought the whole process worked well. Presented the problem and it was investigated.
- Physio, acupuncture, drugs.
- Worked well once I got into the system.
- GP referred straight to the oncologist because not confident to say that the problem was not serious.
- Knowing I could contact more than one person at the hospital.
- Constant communication – keep bugging.
- Had bone scan and was put on medication.
- The GP is the key contact at NHS, telephoned for an appointment. No steps – GP did it. Improved communication between doctors.

What didn't work so well?

- GP not knowing that the illness was linked to the treatment and the after effect of medication.
- Too early to discharge; no regular follow up post remission.
- Over-exercising.
- I personally phoned my hospital from 20 years ago and got the head of department to find my first cancer hospital notes. My oncologist for the second cancer asked me to do it as I could get an answer from them, but she couldn't.
- Getting access to people with access to your notes, so they know history.
- Was never told about radiation-induced salivary damage and the need for special attention to dental care. Dentist also didn't tell me.
- Time delay – one oncology team (adult team) not experienced in childhood late effects/consequences.
- Lack of communication between GP and consultant and transferring data took too long.
- Lymphodema – didn't have any idea.
- Told that the arthritis is a consequence of abrupt menopause, not chemo, although it was chemo that caused the menopause that caused the arthritis.
- X-ray done after radiotherapy treatment because of pain on shoulder .Results came back negative – no action, but pain is still there.

What would you do to improve things?

- Make sure discharge information contains as much information as possible and have the mechanism to fast-track a patient back into the system.
- Listen to the survivors!! They know most. More information for GP's, nurses and Macmillan staff.
- Get the House to pass an Act requiring consultants to obtain properly informed consent, and the insurance companies would soon protest at having to pay out damages.
- Would find out more information before having treatments.
- Teach GP's to listen to patients. Let survivors have a far bigger voice than the professionals.
- Survivorship care plan!! Thank you oncolink.
- GP's to be educated/ compulsory refresher courses so they know how to refer patients on.
- Develop survivorship clinics.
- Specialist referral service by GP – first priority for cancer patient
- More GP awareness – need more accessible info via GP surgery. Encourage use of internet.
- Train health professionals not to belittle patient input on symptoms that could be late effects or signs of recurrence.
- Having one point of contact to help get you the answers you need.
- Educate primary and secondary care.
- Information at A&E – didn't know either. Female B.C patient presenting with unexplained rib break??
- Aftercare plan for me with information on potential set-backs, recurrences. Things to look for.
- More info before treatment about late effects so you can make more informed choices.

How did your care and treatment compare with when you were first diagnosed?

- First diagnosis at age 18 – Hodgkins. Second diagnosis with breast cancer at age 39, consequence of radiation for first cancer. Care and treatment for 'consequence' was non-existent. It was regarded as second primary cancer and treated in a stand alone manner. There was no relation between the medical treatments and professionals of the first and second.
- Less bothered and not important. Less care – less funding??
- Very similar but better in a way too. Fast.
- Poorer and poorer.

Cancer Voices Workshop Feedback

- Didn't have access to Macmillan nurse when diagnosed with secondaries.
- Not interested in you as they are only interested in treating cancer – and they've finished doing that.
- Better flow of aftercare treatment than at original treatment hospital and follow up appointments diagnosed from mammogram.
- Immunologist – suppressed immune system. Opens the door to many other medical or physical problems. Disabilities can often occur.

Well being

Thinking about “well-being” covering a range of physical, emotional and social areas – what service did you access after your cancer treatment?

- Specialist Nurses used by three people, found out about by hospital referrals.
- Psychology used by one person, found out about by hospital referrals.

What other “well-being” services would have helped you after your treatment, but were not available?

- Should be available long term; do people need it more years down the line? – everybody’s needs are different.
- Living life after treatment (Course) through the hospital three months post-treatment. Started last year (2008) (Liz Taylor)
- Transitional help back into school for young survivors – do the educators need educating?
- Chester – Living Life after treatment. Psychological support. Patients/Family after treatment – fatigue, anxiety, financial.
1: CNS gives information (trigger information) three months after treatment.
2: Self help groups – start from it.
Individual needs vary. Education schemes, very supportive. Difficulty in state education. Young children with special needs need tutors.

If you have had a recurrence of cancer or a concern that was not a recurrence:

How did you know what to do/who to see?

- Been in the system for the whole 10 years since first diagnosis.
- No – went to see GP.
- Without a CNS/ 5 years out of the system – don't know what to do, some people go to A&E

How easy was this to make it happen?

- Very easy
- Not easy
- Not easy – don't want "to be a nuisance", professionals are busy – also some people are in denial and there may be a recurrence.

How many steps did you go through before you got to the person you needed?

- One or two.
- Four
- Many and varied

What worked well?

- Good relationship with my medical team
- Breast care nurse services
- Getting through to the key worker (retaining contact information)

What didn't work so well?

- Nothing
- Delay – communication between GP and hospital
- Getting back into the system

What would you do to improve things?

- Ensure every patient is given a CNS (immediately on diagnosis) or key worker.

Cancer Voices Workshop Feedback

- Better communication techniques between GP and hospital.
- GP education and training – diagnosis and recognition of symptoms. Post-discharge link with CNS teams post-treatment.

How did your care and treatment compare with when you were first diagnosed?

- Much, much better
- Better
- Once back in the system, much better