



# A case of... seminoma in a patient with disabilities

By Janet Johnson

## Introduction

Providing outpatient radiotherapy services to patients with disabilities can be challenging on both a practical and emotional level. The legislation, most notably the Disability Discrimination Act (1995)<sup>1</sup> and more recently the Mental Capacity Act (2005)<sup>2</sup>, provides clear responsibilities which we are obliged to exercise in order to maintain a quality service for all.

In last month's *Synergy*, Andrea Hirst summarised practical ways to support those with special needs (*How to make patient services more accessible*). The following case study hopefully illustrates that, with good communication, forward planning and strong liaison between services and organisations, within the context of the law, a positive outcome for both patient and staff is achievable.

## Patient profile

The patient is a 31-year-old male with significant physical and learning disabilities who is cared for in a nursing home. He is unable to speak, read or write, has severe kyphoscoliosis (image 1), is quadriplegic

with bilateral hip dislocation and restricted to a wheelchair. He relies on others for all levels of personal care, little family history is known and there are no family contacts known to the services providing his care. His past medical history notes that he has epilepsy and asthma.

## Presentation

The patient presented to surgical services in a local district general hospital with an inguinal testis. He underwent a left orchidectomy and histology showed evidence of seminoma with invasion into the tunica and epididymis. There was some uncertainty about the surgical margins. Tumour markers and a diagnostic CT scan were performed. AFP and Beta HcG levels were within normal limits, but LDH was raised at 944 and the CT showed para-aortic lymphadenopathy, at the renal hilar level (see image 2). This was staged as a 2A testicular seminoma.

## Clinical background and RT planning

A referral was made from the surgical team to consider further management options. Consideration was given to the risks and benefits

of chemotherapy as opposed to radiotherapy in the context of known co-morbidities. On balance, it was considered that radiotherapy would present the least risk of significant complications for the patient. The plan was to deliver a parallel pair of megavoltage fields to the para-aortic and inguinal regions, delivering a midplane dose of 30Gy in 15 fractions followed by a boost to the involved site of 6Gy in three fractions. The fields were to be planned using CT virtual simulation and a vacuum cushion immobilisation device.

Radiotherapy planning presented a number of issues. The degree of physical disability meant that conventional ant/post fields needed to be significantly modified and custom shaped with MLC shielding to limit the dose to the kidneys – kidney doses were assessed using dose volume histograms (image 3).

### Practical issues

Planning 20 outpatient visits required close liaison between the radiotherapy department, medical staff and carers. Referral came through the normal channels but was accompanied by a supplementary form which we use to provide extra detailed information for those patients with any type of special needs. This described the extent of the patient's physical restrictions, his communication difficulties and a concern about the challenges of achieving a good radiotherapy plan, along with the contact details of the key players in his life.

This form helps the department to quickly gain insight into the services and people who need to be involved at an early stage and has been invaluable in allowing us to implement key services promptly.

The first task was to elaborate on this referral by telephoning the nursing home and discussing the day-to-day issues which affect the patient. It became clear that an assessment visit prior to starting the treatment planning process would help the radiotherapy team to assess the feasibility of planning and delivering the radiotherapy. It would also allow both patient and carers to familiarise themselves with the geography of the department, clearly understand what would be expected of them, and assess accessibility issues.

Because we were planning to use a vacuum cushion immobilisation device, this could be made at the assessment visit. The patient's own hoist was also brought along to ensure that hoisting him directly into the immobilisation device would be feasible and that he felt safe and secure with this process. The departmental manual handling co-ordinator and a staff member trained in the use of the hoist were also present. We were able to assess the patient's ability to remain still and his response to being close to the equipment and being left alone in the room for a period of time. We also needed to ensure that when the gantry was rotated to treat the posterior field, he remained comfortable, secure and still.

The other advantage of this assessment visit was to allow patient and carers to meet the radiotherapy team. Carers shared their knowledge of the patient's communication methods: we learnt that his way of showing pain or disapproval was to close his eyes and turn his head away; we learned about the music he liked and the name he preferred.

At this visit, the nursing home staff also brought along a digital camera to take photos of the staff and equipment. The patient had a photo events diary which he could look through with the

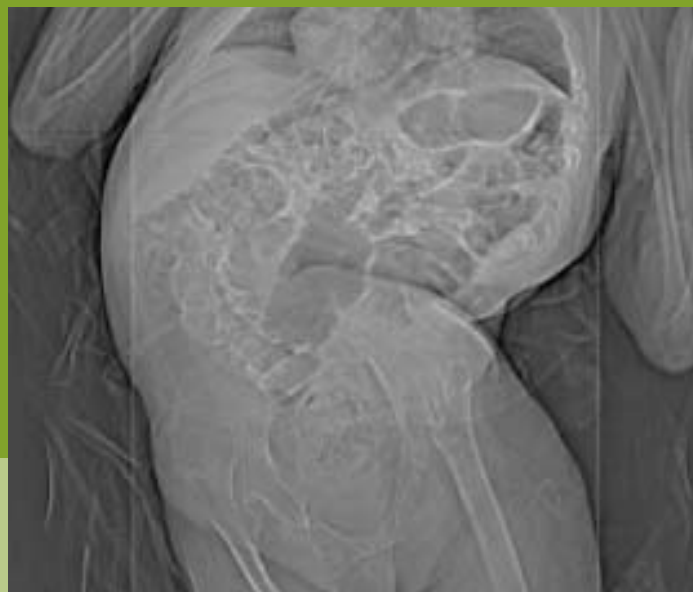


Image 1: This patient has severe kyphoscoliosis.

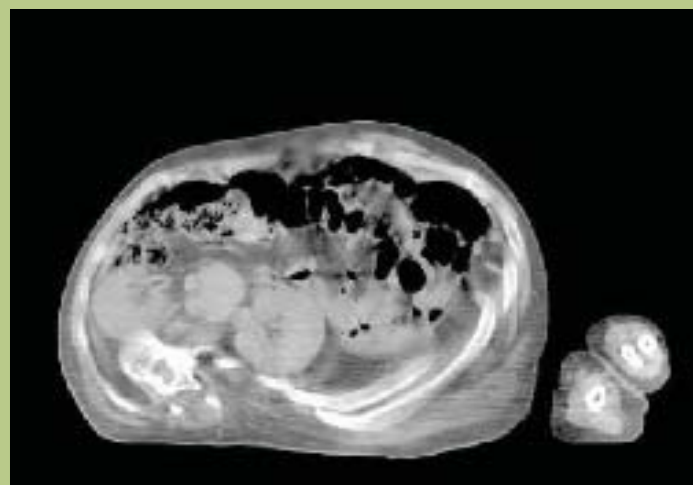


Image 2: An axial image showing retroperitoneal mass at renal hilar level.

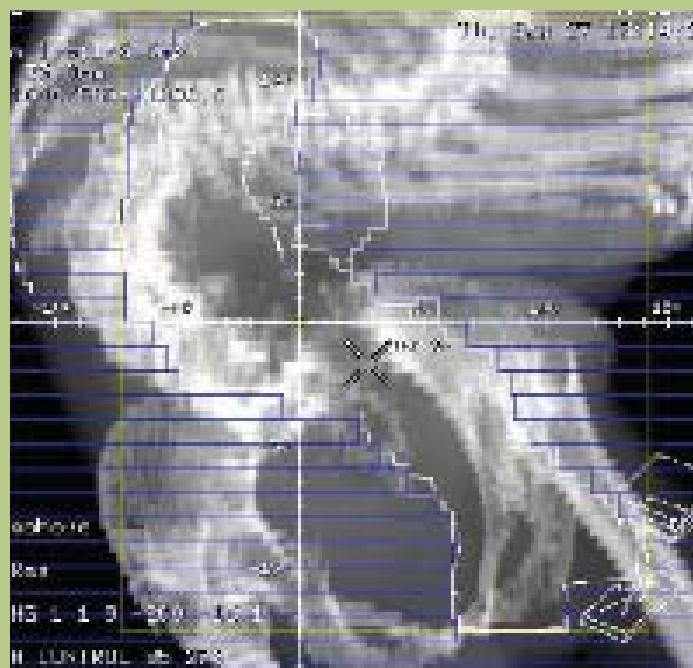
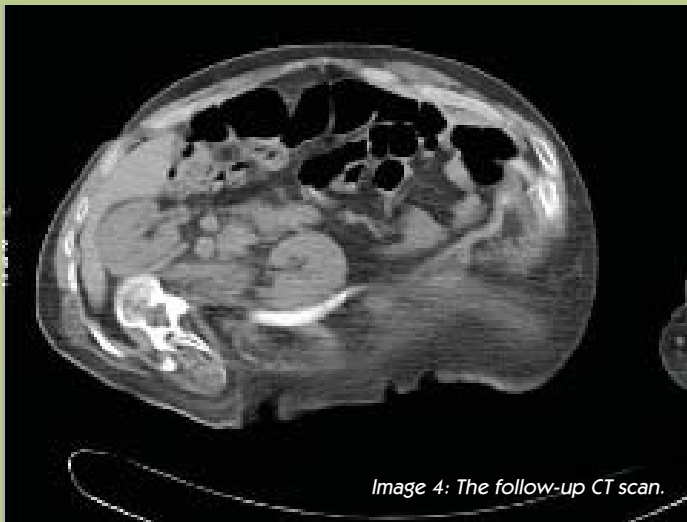


Image 3: Virtual simulation DRR of planned treatment fields.



staff, back in his home environment, to help familiarise himself with the treatment process and the people involved in his care.

### Accessibility issues

Hoisting from wheelchair onto treatment couch was required on a daily basis. The static design of radiotherapy couches, along with restrictions in the treatment room, mean that using hoists can be difficult. It was agreed that the hoisting would be undertaken by two of the carers that he knew and trusted in his daily care. Using their own hoist also meant that he was familiar with the sling and associated equipment being used to transfer him. A manual handling risk assessment was completed during this pre-visit so that all staff were informed of potential difficulties and ways of overcoming them. Declaration of decontamination of the hoist and checking that it had been maintained and was in good working order was also required.

Treatment times and appointment length were negotiated with the carers and a parking arrangement facilitated so that they could attend appointments promptly, reducing unnecessary waiting and avoiding causing anxiety. Assured parking meant that they were also able to transport hoisting equipment quickly and easily.

### Legal/ethical issues

The Mental Capacity Act (MCA)<sup>2</sup>, legislation regarding the process to be used for patients who lack the capacity to make decisions about their treatment, came into force in 2007. Prior to our experience with this patient, an awareness and training drive had been launched throughout our Trust to inform staff of the implications of the Act.

Briefly, it aims to protect and empower adults who may lack the capacity to make important decisions about many aspects of their lives, such as finances, medical care, where they reside or everyday aspects of their lives. The Act makes it clear how to establish an individual's capacity to make a particular decision, who can make decisions if the person is deemed unable to do so and how they must go about the decision-making process.

In our department, we had thought that many of the issues raised by the MCA would not be frequently applicable in the context of radiotherapy. This case meant that, in reality, we had to explore the practicalities of the Act very quickly. For this patient, a serious medical treatment was being proposed and with no relatives/friends actively involved in his care or any that could be contacted to become involved, it became necessary, under the legislation, to seek the

services of an IMCA (independent mental capacity advocate): *The aim of the IMCA service is to provide independent safeguards for people who lack capacity to make certain important decisions and, at the time such decisions need to be made, have no-one else (other than paid staff) to support or represent them or be consulted<sup>8</sup>.*

It is also important to understand what an IMCA is not: *An IMCA will not be the decision maker but the decision maker will have a duty to take into account the information given by the IMCA<sup>3</sup>.*

IMCAs act as independent advocates who will evaluate information available about the treatment to be given, will have access to relevant medical records and, as far as is possible, represent the wishes and feelings of the patient based on available information. Finally, they provide a report either supporting or challenging the decision and any information provided by the IMCA must be taken into account by the decision maker.

We made a referral to enlist the services of an IMCA to assist this patient through the process of his treatment and to oversee that due process was being carried out. We found the process of referral straightforward and the IMCA's input helpful, supportive and reassuring that a quality service was maintained for the patient.

She attended on each of the initial planning visits, interviewed key staff about the proposed treatment and was involved with the consent process. She needed the treatment procedure to be thoroughly explained to her to understand what the patient needed to do, and she also reviewed the standard information provided to patients receiving radiotherapy for seminoma in order to ensure that she understood the treatment process, the acute and long term side effects and implications of treatment, etc.

### Treatment delivery

With a significant amount of forward planning and liaison, the treatment delivery aspect went very smoothly. The patient coped very well with the daily visits and experienced few side effects. Anti-emetic cover ensured that the patient showed no evidence of nausea/vomiting but was reportedly fatigued during the latter half of the treatment course. A follow up diagnostic CT three months post radiotherapy showed a significant reduction in the size of the retroperitoneal mass (image 4).

### Conclusion

In delivering radiotherapy to this patient, we had cause to address most of the issues noted in last month's article – communication

issues, access difficulties and legal and ethical issues. In this instance, the treatment was delivered as accurately and efficiently as possible with minimal distress to the patient. This was achieved by thorough assessment, co-operation between services, a commitment to forward planning and due regard for the law.

It is undoubtedly the case that patients with a significant disability which impacts upon their ability to consent to treatment or achieve the required position for treatment, make up the minority of patients within a radiotherapy department. However, it is becoming increasingly clear that we will, in future, see changes in the client profile accessing health services.

Patients with learning disabilities are generally experiencing an increase in life expectancy as a result of health and technological advances<sup>4</sup>. Consequently, by encouraging them to engage with screening services and with an improvement in the willingness of clinicians to treat, we will no doubt see that many people with physical and learning disabilities will increasingly require the input of health services for treatment of diseases linked with old age.

However, despite the implementation of government strategies and an increasing recognition of the particular difficulties faced by those with disability when accessing health services, Mencap reports that many health services are still not providing equality of care for those with learning disabilities. They note particularly that this is often because healthcare staff do not recognise and understand the needs of those with learning disability and hence cannot provide quality care<sup>5</sup>.

A specific example of this is in relation to the provision of information. Research has shown that there is still a distinct lack of cancer information materials designed for and aimed specifically at those with intellectual disability and this can result in them being prevented from making informed decisions about their own care or understanding the care of a family member with cancer<sup>6</sup>.

Radiotherapy departments, along with all other health services, have a moral and a legal obligation to provide high quality services which meet the needs of the disabled – this does not only mean provision of appropriate resources, information and access, but it also requires the training and development of a workforce with the skills, commitment and confidence to provide a quality service for all.



## How to use this article for CPD

This study can be used to generate a range of further learning activities:

The introduction refers to two pieces of legislation which have a potential impact on the care and management of patients with disabilities. You might look for more information about the two Acts referred to and see if you are able to find specific guidance pertinent to their application within your practice. What guidance has the Society published recently in this area? Have a look at the document library on the Society's website.

With regard to practical and accessibility issues, you might consider how these would be addressed in your own department, using the equipment that you have. Is this equipment adequate? If not, what are the implications from practical, ethical and legal points of view?

Do the legal and ethical issues raised alert you to the possibility of changes that might need to be made in departmental procedures and policy? How might these be implemented?

Do the points raised in the conclusion indicate any areas where a review of current departmental practice might be appropriate? How feasible is change? How might it be brought about? What are the resource issues?

Access the documents cited in the reference section (you will find these in electronic format on the SoR website). You can use these as the basis for personal reflection or discussion with colleagues.

**CPD Now** outcomes that may be covered by these activities include:

- 01 Practical skills
- 02 Knowledge base
- 03 Work safely
- 04 Legal and ethical
- 05 Communication skills
- 08 Patient centred care and choice
- 12 Service design and management

**Sean Kelly, CPD officer**

### About the Author


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References for this article are at: [www.sor.org/members/pubarchive/pub\\_search.htm](http://www.sor.org/members/pubarchive/pub_search.htm)

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