

PRACTICE POINTER

Communicating in a healthcare setting with people who have hearing loss

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Many patients with hearing loss find communication in healthcare settings difficult, and this might sometimes affect their care. This article outlines how staff can best communicate with people with hearing loss

In the United Kingdom one in seven of the population (more than six million people aged over 60 and two and a half million aged 60 and under) have a hearing loss.¹ Hospital services are used more by older people,² so many of the patients seen by health professionals have a hearing loss. Staff often do not appropriately adapt the way they communicate with this group.³⁻⁵

Most people with a hearing loss have either developed the problem in later life (the vast majority) or acquired a loss through, for example, infection or trauma. Nearly all these people communicate with spoken language and may also use hearing aids. A small proportion of people with a hearing loss are congenitally severely or profoundly deaf and are more likely to use sign language. For clarity of terminology, throughout this article we use the term deafness and deaf people to refer in general to hearing loss of all types and degrees and to those who are affected.

Deafness can affect a person's ability to communicate properly. It alters their interactions with others and may contribute to depression, anxiety, loneliness, and social withdrawal.⁶⁻¹¹ Deaf people complain that medical professionals frequently lack understanding and empathy.¹² Often they feel that health professionals do not appreciate just how stressful it is to engage in a healthcare setting; this problem primarily results from inadvertent barriers that prevent effective communication. Health professionals could benefit from special training in how best to deal with the communication difficulties of deaf patients.⁵ Indeed the Department of Health in England recommends that all frontline National Health Service (NHS) staff should have "deaf awareness" training.¹³ In this article we highlight how people's deafness affects them in healthcare settings. We also provide advice and resources on how to meet the communication needs of deaf patients. Box 1 outlines the terminology usually used by people to describe their deafness.

The need for appropriate communication skills

The Royal National Institute for Deaf People (RNID) is the UK's largest charity representing deaf people. In 2004 it

Box 1 | Terms used by deaf people to describe themselves

- The term **hearing impaired** is used more often by health professionals than by individuals. Impairment is defined by the World Health Organization's *International Classification of Functioning, Disability and Health*¹⁴ as "problems in body function or structure such as a significant deviation or loss" which "represent a deviation from certain generally accepted population standards in the biomedical status of the body and its functions." Indeed, most charities and support groups for deaf and hard of hearing people no longer regard the term hearing impaired as politically correct and have dropped the use of this.
- The description **deaf** tends to be used by people who are profoundly deaf and who use spoken language. Such people will often use lipreading and may gain benefit from a hearing aid or cochlear implant; they may have a congenital deafness or have lost their hearing as a child or young adult. The term might also be used by anyone who has developed a mild to moderate deafness as an adult, who might say of themselves "I'm a bit deaf." They too will often use lipreading and may benefit from a hearing aid.
- People who call themselves **Deaf** (with an upper case "D") usually use sign language as their first language and consider themselves "culturally" deaf (that is, they regard deafness as a difference in human experience rather than a disability).¹⁵ They usually have profound deafness, which may be congenital. They may use some lipreading but often prefer to communicate directly in sign language; they may gain little benefit from written material.
- The term **hard of hearing** may be used by someone who has mild to severe deafness, which may be progressive and has usually started in older age. They often use lipreading, reading, and written communication and may gain benefit from a hearing aid.
- The description **deafened** is usually used by someone with spoken language who became deaf as an adult; often they have profound deafness (which may have occurred suddenly) and may not derive much benefit from a hearing aid or cochlear implant and thus may rely heavily on lipreading and using reading and writing.

published a report on the experiences of 866 deaf people across the UK and their views of using various health services.¹⁶ In its survey it found that 42% of respondents who had visited hospital had found communication with NHS staff difficult; this figure increased to 66% for people who used British sign language (BSL). Most worrying was that a third

of respondents said they had taken the wrong dose of a particular medicine through not understanding what they had been told. These findings illustrate how important it is for all health service staff to have appropriate communication skills. The Disability Discrimination Act 2005 requires hospitals to make all reasonable adjustments to enable patients to access services. Enabling access for deaf people is inextricably linked to the facilitation of good communication.

What difficulties do deaf patients experience?

The extent of difficulties for deaf patients depends on the duration and cause of their deafness, their usual means of communication, and how much support they have.¹⁷⁻²⁰ Their experience can also be affected by how they view themselves and their deafness (box 1)²¹ and whether they have a family history of the condition.²²

Many health related situations arise in which deaf people have difficulties.^{18-20 23-30} They may not hear clearly on the telephone and so using a telephone booking service for appointments can be stressful. Noisy reception areas may make it difficult to hear necessary information. A receptionist, who looks straight at the computer, rather than at the patient, is difficult to lipread; so too is a doctor who talks while continually flicking through medical records.

Lipreading is not easy when trying to navigate regional accents; it is also difficult when lying down because faces need to be easily seen. It becomes impossible when a doctor or nurse wears a mask. The problems may be intensified in an operating theatre if the patient has arrived there dulled by the sedative effects of medication and without hearing aids or glasses.

Deaf patients may become isolated if unable to join in conversation with other patients, visitors, and ward staff. The resulting isolation may have a detrimental effect on wellbeing and recovery.^{6-8 11 23} Hospedia (hospitals' bedside phone and media service for patients) and dayroom televisions without subtitle facilities make television inaccessible. Some hospital telephones do not have text, loop systems, or amplification facilities to enable deaf patients to keep in touch with their families.²⁸

Misheard diagnoses or instructions can understandably lead to anxiety, embarrassment, and depression.^{6-8 29} Deaf people may experience rapidly changing confidence depending on stress levels, situations, and communication barriers. As communication breaks down with no obvious solution, the patient may continue to struggle on through the conversation without having the confidence to ask the health professional to stop. It is up to the health professional to pick up on signals from the patient and take appropriate action to rescue the situation.

How to improve communication with deaf patients

Perhaps the most important message for health professionals is that they already hold the key to tackling many of the necessary deaf awareness matters—empathy. By thinking about what it might feel like to spend a day as a deaf person, we can improve our communication without any grand gestures. It is tiring for deaf people to have to deal constantly with other people's reactions, stereotypes, and impatience and to struggle to listen to a conversation that they cannot hear. It is embarrassing for them to ask for things to be repeated.

Box 2 | Tips for communicating with deaf patients

- Get the person's attention before speaking
- Ensure the person knows what is being discussed
- Face the person while speaking
- Maintain eye contact (stand or sit on the same level as the patient, three to six feet away)
- Speak clearly and a little more slowly than usual
- Shouting will only distort the pattern of speech, making it more difficult to understand
- Do not cover your mouth when speaking
- Do not exaggerate mouth movements
- Rephrase rather than repeat
- Indicate when you intend to change to a new topic because the range of vocabulary is likely to be different
- Use "signposting" in the conversation, such as "I'm going to ask about your symptoms first and then I'll do a physical examination second"
- Any cue is useful—use mime, gesture, and body language
- If you have to examine the patient explain clearly, before you begin, what you are going to do and how you wish him or her to cooperate
- Use pen and paper if necessary
- Write down instructions about taking treatment
- Use open ended questions
- Be patient—check that you have been understood
- For patients who use BSL, use an interpreter or provide live access to an online interpreter; both these options may have to be arranged in advance
- If you are sending a patient to another department—for example, for radiography—put the communication needs on the request form
- Mark all medical notes clearly on the front with the patient's communication needs—for example, "needs lipspeaker [name, telephone number]" or "good lipreader, finds written notes helpful"

Health professionals need to be observant, consciously reflect on adapting their communication, take additional time, repeat and rephrase conversation, and anticipate what might be helpful. Box 2 outlines some useful tips for communicating with deaf people.

Consider the environment

Background noise

Deaf people may find it difficult to follow a conversation in noisy environments. It may therefore be appropriate to move to a different consultation room or quiet corner of a ward. Shutting doors and windows may also help. Many hearing aids make it difficult to determine the direction of sound—for example, a user may hear that someone has spoken but cannot determine who. This can cause embarrassment when responding to the wrong person.

Lighting

Lipreading and the reading of body language are more difficult when the lighting is compromised. The face of the person talking to a patient with hearing difficulties needs to be in a good light so that the patient can lipread clearly. Avoid standing in front of a light source, such as a window or bright light.

Booking an appointment

Many deaf people use devices that help them use the telephone. For example, they may add an amplifier to their phone to increase the volume of the person speaking to them or may use Text Relay (www.textrelay.org), an operator assisted service that enables a conversation to take place between someone using a textphone and someone using a standard phone. The deaf person types a message into their own phone and the telephone operator reads this out to the hearing person at the end of the

line. It is vital that hospital reception staff are familiar with making and receiving calls in non-standard ways. They must use facilities to accept text messaging (such as via a hospital mobile phone) and also email and online messaging.⁵

The waiting room

Adding a loop system to the reception desk in a waiting room can help hearing aid users. Ensure that the loop system is switched on and that reception staff know how it works. Waiting for a consultation is one of the most stressful times for deaf people, and health professionals should not underestimate the emotional energy expended by a patient who is worried they are not going to hear their name called. If all chairs in a waiting room face the reception desk, patients who lipread can more easily look up and see a health professional call their name. Use of a notice board so that patients can easily see their name indicating their turn is also helpful; although this system is not ideal for protecting confidentiality, it is popular in many hospital departments. Another successful system is to give a pager to patients when they arrive that will vibrate when it is their turn.

Use the help of a communication support worker or interpreter

Many different types of interpreters and communication support workers are trained in helping in communication with deaf people. For a person who uses mainly lipreading, a professional “lipspeaker” may be helpful. The lipspeaker sits next to the healthcare worker and mouths the words that are being spoken, using clear lip patterns and finger spelling (a way of spelling out words). Alternatively, a “speech to text” reporter or a note taker can be helpful, as they turn the spoken conversation into a written form for the patient. It is vital to implement these options for long consultations; patients who rely mainly on lipreading should not be expected to lipread a full consultation with no additional support. Even excellent lipreaders will follow only about 30% of any conversation.²⁹

For patients who use sign language, employ a BSL interpreter. The most important factor is to ask patients if they need additional communication support and what sort of professional they prefer to work with. Details of appropriate, accredited interpreters who are familiar with working in a health setting can be found on the National Registers of Communication Professionals who Work with Deaf and Deafblind People (NRCPPD) (www.NRCPPD.org.uk).

BSL is a language in its own right, not a literal translation of spoken language; therefore a BSL user may not find it easy to follow a conversation in spoken or written English. Thus just speaking louder or even writing notes is unlikely to be of any use.⁵ Research has shown that most BSL users prefer to have a healthcare consultation either with a signing health professional or via an interpreter; only a small minority could cope with a consultation conducted entirely in speech, particularly if the health professional was unaware of how to communicate well with deaf people.^{5 31}

INNOVATIVE COMMUNICATION SOFTWARE

Many hospitals are now using innovative methods to meet the communication needs of their deaf patients. At the Royal United Hospital in Bath a “computer on wheels” is used across the hospital to aid communication. It comprises a laptop with a wireless internet connection and webcam on a frame, which can be easily wheeled to a patient’s bedside or a consultation room. The computer contains software that enables access to a live, online BSL interpreter. The same software also enables access to 500 medical phrases, so if the patient arrives out of office hours they can use the system to aid communication if an interpreter is unavailable. The software also allows access to standard phrases in several different languages, such as Polish, Urdu, and Punjabi. This software is available to every general practice surgery across England and can also be easily acquired by hospitals (see www.signtranslate.com).

PERSONAL EXPERIENCES

Example 1

“The curtain was around the bed and the doctor came in and examined me. Then he disappeared. I thought he’d gone to get something so I stayed in this rather undignified position. After a while I became concerned and began to wonder if there was something amiss. I knew he was still in the room because I could hear his voice but not what he was saying. I thought perhaps he was making a call to another doctor or something. I didn’t know what to do and was feeling quite distressed, when he popped his head round the curtain and said ‘Why aren’t you getting dressed?’ I didn’t try to explain because I was worried about taking up even more of his time.”

Example 2

“I’ve been deaf since birth and use BSL as my first language. I broke my left arm and sprained my right wrist in a car accident and arrived in the accident and emergency department in pain and in shock. Because I couldn’t clearly sign due to my injuries and also have unclear speech, the doctors didn’t understand what I was saying. They seemed to assume I had learning difficulties whereas I am actually a university lecturer. They were confused as to why I wasn’t wearing a hearing aid. A sharp junior doctor clicked that I was Deaf; this was such a relief. She asked me via a written note how I wanted the team to communicate with me. I pointed to the iPhone in my pocket—on there I had some instructions about interpreters I use as well as software that health professionals can use to communicate with BSL users.”

Example 3

“I went for an ECG. A young man showed me to a cubicle, told me to sit and wait and he’d be back in a few minutes. When he came back he looked puzzled and said, ‘Did you need some help?’ I replied, ‘You told me to sit and wait.’ He said, ‘No, I asked you to strip to the waist.’ We laughed about it and I took the opportunity to spread a bit of deaf awareness while he did the ECG. It didn’t seem so funny when we thought about the misunderstanding in reverse.”

Example 4

“I went for a ‘well woman’ examination. After listening to my chest with a stethoscope the doctor said ‘We’ll do your breasts now.’ I removed my bra and waited. Then he realised and said, ‘No, I said you can get dressed now.’ I was very embarrassed.”

Example 5

“I joined a new general practice. I always find it incredibly stressful waiting to be seen as in the past I haven’t heard my name being called out and have only realised I have missed my appointment when the clinic closed and I was the only one still left. At the new practice I was given a pager on arrival and told it would vibrate when it was my turn. For the first time in my life I was able to relax while waiting and even read a magazine. I didn’t have to constantly watch the reception staff or feel ready to pounce every time a consultation door opened.”

USEFUL RESOURCES FOR HEALTH PROFESSIONALS, PATIENTS, AND STAFF

Royal National Institute for Deaf People (RNID) (www.rnid.org.uk/)
UK charity offering services, technology, and information for deaf and hard of hearing people

Royal Association for Deaf people (www.royaldeaf.org.uk)
UK charity that provides support, advocacy, and services for deaf people

British Deaf Association (www.bda.org.uk/)
Major UK charity run by Deaf people (that is, those who use BSL)

Hearing Concern Link (www.hearingconcernlink.org)
Provides support and information to hard of hearing and deafened people

Association of Teachers of Lipreading to Adults (www.lipreading.org.uk)
Professional association for teachers of lipreading to adults who have become deaf

UK Council on Deafness (www.deafcouncil.org.uk)
Works with and for deaf organisations in the UK by providing information, advice, and support and by representing the views of the sector to government and policy makers

Scottish Council for Deafness (www.scod.org.uk/)
Lead organisation for deaf issues in Scotland, representing 90 organisations that are working with and on behalf of deaf and deaf-blind people

National Registers of Communication Professionals who Work with Deaf and Deafblind People (www.NRCPD.org.uk)—Website for finding an accredited interpreter and communication support worker in the UK

Signature (www.signature.org.uk)
Website giving information about different types of communication support work, plus training and qualifications of support workers

Text Relay (www.textrelay.org)
Telephone service for communication via an operator between deaf, text based phone users and hearing, speech based phone users

Physical examinations

During a physical examination it is important to retain eye contact as much as possible so that the patient can clearly see when the doctor intends to make physical contact. If the doctor wishes to talk to the patient while examining them then he or she must be clearly visible when speaking. It is often helpful to agree a method of communication before the examination starts. For example, say to the patient “during the examination, I will move around the room. If I need to speak to you I’ll touch your arm first.” This way the patient knows that the doctor is speaking to them and not to the attendant nurse.

Conclusion

Communication is a two way affair, not the sole responsibility of the deaf person.³² Deaf patients and their relatives need to be able to attend healthcare settings without worrying about difficulties with communication and potential untoward impact on their health care. We believe that increased awareness and knowledge among healthcare staff on how best to communicate with deaf people will improve the quality of care provided to this important group of patients.

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- Royal National Institute for Deaf People. Facts and figures on deafness and tinnitus. (Internal publication, based on work from the MRC Institute of Hearing Research, University of Nottingham.) 2006. www.rnid.org.uk/VirtualContent/101697/Facts_and_figures_on_deafness_and_tinnitus_March_2006.pdf.
- Hospital Episode Statistics. 2010. www.hesonline.nhs.uk/.
- Barnett S. Communication with deaf and hard of hearing people: a guide for medical education. *Acad Med* 2002;34:376-82.
- Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P. Health care system accessibility: experiences and perceptions of deaf people. *J Gen Intern Med* 2006;21:260-6.
- Middleton A, ed. Working with deaf people: a handbook for healthcare professionals. Cambridge University Press, 2010.
- Jones BL. Integrating hearing loss was a complex and dynamic process for patients. *Evid Based Nurs* 1998;1:131.
- Dalton DS, Cruickshanks KJ, Klein BE, Klein R, Wiley TL, Nondahl DM. The impact of hearing loss on quality of life in older adults. *Gerontologist* 2003;43:661-8.
- NHS Quality Improvement Scotland. Maximising hearing disability. 2005. www.nhshealthquality.org/nhsqis/2776.html?pageSize=largest.
- Davidhizar R. When your patient cannot hear you. *J Pract Nurs* 2008;58:12-5.
- Brink P, Stones M. Examination of the relationship among hearing impairment, linguistic communication, mood, and social engagement of residents in complex continuing-care facilities. *Gerontologist* 2007;47:633-41.
- Zazove P, Meador HE, Aikens JE, Nease DE, Gorenflo DW. Assessment of depressive symptoms in deaf persons. *J Am Board Fam Med* 2006;19:141-7.
- Mackenzie I, Smith A. Deafness—the neglected and hidden disability. *Ann Trop Med Parasitol* 2009;103:565-71.
- Department of Health. Mental health and deafness: towards equity and access. (Best practice guidance.) 2005. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4103995.
- World Health Organization. International classification of functioning, disability and health. 2001. www.handicapincifre.it/documenti/ICF_18.pdf.
- Stephens D, Danermark B. The international classification of functioning, disability and health as a conceptual framework for the impact of genetic hearing impairment. In: Stephens D, Jones L, eds. The impact of genetic hearing impairment. Whurr, 2005:54-67.
- Royal National Institute for Deaf People. A simple cure. 2004. www.rnid.org.uk/VirtualContent/84923/asimplecure.pdf.
- Saunders GH, Echt KV. An overview of dual sensory impairment in older adults: perspectives for rehabilitation. *Trends Amplif* 2007;11:227-32.
- Hickson L, Scarinci N. Older adults with acquired hearing impairment: applying the ICF in rehabilitation. *Semin Speech Lang* 2007;28:283-90.
- Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P. Health care system accessibility. Experiences and perceptions of deaf people. *J Gen Intern Med* 2006;21:260-6.
- Traynor N, Lucas S. Ensuring deafened patients can participate in their health care. *Nursing Times* 2004;100:32-4.
- Ladd P. Understanding deaf culture: in search of deafhood. *Multilingual Matters*, 2003.
- Fortnum H, Barton G, Stephens D, Stacey P, Summerfield AQ. The impact for children of having a family history of hearing impairment in a UK-wide population study. In: Stephens D, Jones L, eds. The effects of genetic hearing impairment in the family. Wiley, 2006:29-42.
- Iezzoni LI, O'Day BL, Killeen M, Harker H. Communicating about health care: observations from persons who are deaf or hard of hearing. *Ann Intern Med* 2004;140:356-62.
- Slaven A. Communication and the hearing-impaired patient. *Nurs Stand* 2003;18:39-41.
- Steinberg AG, Wiggins EA, Barmada CH, Sullivan VJ. Deaf women: experiences and perceptions of healthcare system access. *J Womens Health (Larchmt)* 2002;11:729-41.
- Hines J. Communication problems of hearing-impaired patients. *Nurs Stand* 2000;14(19):33-7.
- Witte TN, Kuzel AJ. Elderly deaf patients' health care experiences. *J Am Board Fam Pract* 2000;13:81-3.
- Mann WJ. Telephone communication when the patient is deaf or hard-of-hearing. *Md Med J* 1994;43:509-10.
- Harmer LM. Health care delivery and deaf people: practice, problems and recommendations for change. *J Deaf Studies Deaf Education* 1999;4:73-110.
- Middleton A, Emery SD, Turner GH. Views, knowledge and beliefs about genetics and genetic counselling amongst people with deafness. *Sign Language Studies* 2010;10:170-96.
- Middleton A, Turner GH, Bitner-Glindzic M, Lewis P, Richards M, Clarke A, et al. Preferences for communication in clinic from deaf people: a cross-sectional study. *J Eval Clin Pract* 2010;16:811-7.
- Baker H, Crockett R, Uus K, Bamford JM, Marteau T. Why don't health professionals check patient understanding? A questionnaire-based study. *Psychol Health Med* 2007;12:380-5.

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A PATIENT'S JOURNEY

At sixes and sevens: prostate cancer

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

The patient recounts how two months after radical prostate surgery he developed a thick walled and deeply embedded abscess, which required difficult and complicated surgery

As the car swung into Swing-Swang Lane, on our final approach to the clinic, I still felt symptomless but had the eerie knowledge that the next day my abdomen was going to resemble a cage fighter's and I would be doped up to the eyeballs. At the age of 53, my prostatic tumour had been diagnosed early, and I had opted for surgical extirpation.

There are some 34 000 new cases in the United Kingdom every year, and it seems everyone from the Lockerbie bomber to Adrian Mole (aged 39¼) has prostate cancer; it may be the most common internal malignancy for Western men, but when they break the bad news to you it comes as a complete surprise. After several years of fluctuating prostate specific antigen values (settling around 6.1 µg/l), and despite two negative PCA3 urine tests, I finally underwent biopsy needle sampling, the results of which showed that I had a bulky adenocarcinoma (Gleason score 6-7) at clinical stage T1c. Hearing this was one of my life's low points. In Aidy Mole's phrase, "I felt like a ghost of myself."

Numbly, I considered the options. I kept perusal of internet mumbo-jumbo to a bare minimum, studied the helpful National Institute for Health and Clinical Excellence (NICE) website, and was finally convinced by consultant urologist Christopher Eden that the default option should be interventional surgery, keeping radiotherapy as a possible back-up. He proposed a laparoscopic radical prostatectomy, and it sounded quite alarming (I am notably squeamish). The location of the offending gland is most inconvenient—how much simpler if it were in the left ear lobe—and faced, during the preoperative briefing, with nappies, bags, and straps, I wondered queasily if I had plumped for the right treatment. Roll on the day when it can be tackled with a retrovirus vaccine or high intensity focused ultrasound. Perhaps I should have popped into my local Chinese herbalist for a nice cup of golden lock tea. In the middle of all this, Dr Donald Gleason himself died in Minnesota, which I found strangely unnerving.

On the appointed day, I trudged towards the anaesthetics room like a Junior Colts batsman going out to face the first eleven's demon bowler. "I'm not awfully good with needles or blood," I confessed to one nurse. "You're in the wrong place today, then," she joked. When I came round, I was supine (certainly not prostrate), catheterised, and wind-bound. In my sleep, someone seemed to have punched me five brand new belly buttons. It was Friday the 13th, and Comic Relief Day, to boot.

The procedure had gone well, and Mr Eden had skilfully even managed to preserve my neurovascular bundles. I was hugely relieved. Before long, I was coping with my gory thigh bag, shuffling like an oldster along the corridor (distinctly unathletic in my tracksuit bottoms), and beginning pelvic floor exercises. "Did anyone mention the risk of swelling," asked nurse Marie, "of the testicles?" Now they tell me. I longed to go home, but even so there was a glimmer of Stockholm syndrome when the time came to leave the safety of the clinic's facilities.

Back with my family I was cantankerous and exhausted. The home hydraulics of drainage tubes and sponge baths temporarily distracted me from the long road ahead—an obstacle course combined with snakes and ladders. I had the usual worries (though drastically new to me): Did they get it all out? Will I ever be continent again? Have I kissed goodbye

A CLINICIAN'S PERSPECTIVE

David Profumo recounts his journey through screening, diagnosis, and management of organ confined prostate cancer. With the exception of developing a rare complication, which presented in a most unusual and convoluted way, he describes a journey typical of that taken nowadays by many men throughout the Western world. He is continent, potent, and apparently cured, albeit at a relatively high cost in terms of morbidity, of a condition that had not bothered him to any great extent and the course of which is neither predictable nor fully understood.

The presentation, investigation, and management of prostate cancer have undergone dramatic changes in recent decades. Huggins won a Nobel prize in 1945 for discovering that the disease was hormone sensitive. It was not until the 1980s, however, when Patrick Walsh described the modern version of radical prostatectomy and prostate specific antigen was discovered that it became possible to detect and safely treat the disease before it became locally advanced or metastatic. In parallel with these advances, huge changes have come about in the delivery of radiation to the prostate, both with implantable seeds (brachytherapy) and via external beam. These treatments are delivered with curative intent and acceptable morbidity.

As a result of screening, greater awareness of the condition, and the early investigation of lower urinary tract symptoms secondary to presumed benign prostatic enlargement, more and more men in the United Kingdom are being diagnosed with early prostate cancer. They are faced with difficult decisions at every step of their journey, from whether or not to undergo a transrectal ultrasound and biopsy, to which treatment to opt for if the biopsy is positive. Matters are further complicated by the fact that the histology has to be interpreted in terms of the grade of the tumour, the number of positive cores, and the proportion of cores involved. Once the diagnosis is confirmed the disease has to be staged, in selected cases with further imaging, usually a bone scan and an magnetic resonance imaging scan. All this information then has to be processed while crucially taking into account the patient's age and comorbidities.

Nowadays, in the UK, all patients with a diagnosis of prostate cancer should be discussed at a multidisciplinary team meeting (urological surgeons, radiotherapists, oncologists, pathologists, radiologists, and nurse specialists). One of the roles of this group is to make recommendations to the patient as to what options are suitable for them. In many cases all options are suitable—from active surveillance formerly known as "watchful waiting," through radiotherapy, to surgery, which can be a traditional radical retropubic prostatectomy by the laparoscopic route (as chosen by this patient) through to robotic surgery (not to mention high intensity focused ultrasound and cryotherapy, where available).

I do not envy those who have to make the decision, and at the end of many consultations I am asked "but what would you do if you were me?"

David Profumo's journey, with the exception of his rare complication, is one that is being undertaken by more and more men up and down the country. I think his own guess as to the aetiology of the complication is probably correct. Huge advances have been made in minimally invasive surgery and non-invasive treatments, which has raised expectations, but when complications—especially rare ones—occur, the already vulnerable patient can be further demoralised. This story highlights the fact that more than ever we must try to identify those men who truly need to be treated and which intervention is best for them.

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► Joint hypermobility syndrome
(*BMJ* 2010 341:c3044)

to my love life? I made some feeble joke about my career as a porn star probably being over. My scrotum resembled two purplish figs, and I had chronic constipation. Then, 10 days later, I returned to the clinic for my decatheterisation, miraculously voided a healthy stream, and was released to convalesce in the Scottish Highlands.

I was feeling nicely on the mend, when one morning in early April I simply could not pass urine. After phone advice from down south, we drove for the accident and emergency department in Perth. They had no urologist, but, at 30 miles away, it was considerably closer than Dundee, and the matter was becoming urgent. Major road works en route caused an unwelcome blockage of another type, and by the time we reached the Royal Infirmary my kidneys were aching and I thought I was going to burst. Recatheterised in the nick of time, it seemed a small clot must have clogged my waterworks. I was gloomy about getting the bag back, but, as one of the nurses said, I wasn't about to do much mountain biking anyway.

On 28 May—more than two months after surgery—I suddenly became febrile. For a week I had malarial-style night sweats, spiking temperatures, and general debility. Like an idiot, I was in denial about these symptoms because I was determined to go on a trip with my angling club. Soon after, I could ignore the situation no more, and, fearing I might have caught swine flu (then all the rage), I was admitted to London's Cromwell Hospital with “pyrexia of an unknown origin.” Tests ruled out several countryside related possibilities, such as brucellosis and Lyme disease, but subsequent imaging showed an infected pelvic collection. This was aspirated percutaneously, antibiotics were applied, the fever disappeared, and I was duly discharged.

That weekend, my temperature again undulated, and topped 105°F (40.55°C) (I possess elderly thermometers). My new surgeon, Michael Dinneen, admitted me at once to the Chelsea and Westminster Hospital, a few streets from our house, where a further scan showed ongoing accumulations in what was probably a retropubic abscess. Another small drain was inserted under local anaesthetic—not much fun—and some gruesome matter, which looked to this layman like rancid yoghurt, was siphoned out.

What with all the blood tests being taken and chemicals being fed through cannulas, I was now cured of my old squeamishness, but we were baffled by what was going on in my nether regions. My already weakened bladder, continually being topped up before scans, was also seriously confused. Antibiotics weren't really working, so Mr Dinneen presented the option of drainage by open surgery—no fun at all—but this was now beyond a joke.

When he went in, he found “an extremely thick walled indurated collection of dead purulent matter,” a deeply embedded lymphocele the like of which he had rarely encountered. It proved obdurate, and required “a difficult and complicated operation.” When I came round this time I had a stapled wound six inches wide (there goes my bikini line) and yet another urethral catheter. Talk about snakes and ladders. For a fortnight I lay there, enervated, demoralised, and altogether mystified. My second convalescence was slow, and by the time I was allowed to take a bath again I had even forgotten the automatic routine for drying myself.

The wound culture showed carboxyphilic streptococcus, but no one seemed to know the cause of the complication—my own guess is that the obstruction I had while in Scotland must have caused a tiny leak of urine through the mending tissue, which infected the fluid in my abdominal cavity. When I described all this in an email to an American friend, he merely responded, “Yikes!” I think that just about sums it up.

Given its physiological “zip code,” prostate surgery is quite a big ask of the human body. I still experience occasional enuresis, and I continue to be ably supported by vardenafil, but in retrospect I would say that the side effects are a worthwhile swap for the cancer. Recent trips down Swing-Swang Lane have indicated that I have not had any biochemical relapses, and my final histology showed only Gleason grade 6—so I remain hopeful. Right now, whenever I am told the results of a prostate specific antigen test, my favourite word in the English language, definitely, is: “unrecordable.”

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A sweet cure for a cow in distress

As a trainee in general surgery in rural Shropshire, I was asked by a frustrated cattle farmer if I could help him with a cow that had prolapsed its uterus after parturition. Having had some obstetric and gynaecological experience, I discussed the various procedures for managing the prolapse in humans. None of these seemed appropriate for use on the bovine species. However, when I suggested he pour a bag of sugar on the uterus, as I had done to reduce a prolapsed rectum, the farmer sought to apply the technique.

The next morning there was a knock on my door, and a jubilant farmer told of the success of the new uterine reduction technique. This technique was repeated five times during that calving season, with full reduction in all cases.

The occurrence of uterine prolapse in cows is 0.6%, with a two week mortality of 20%. The prolapsed organ becomes oedematous, and reduction becomes difficult and painful. The application of sugar or even salt will cause a decrease in size as the organ loses fluid through osmosis. The organ, either uterus or rectum, then either self reduces or becomes much easier to reduce.

I don't know of any randomised trials comparing the sugar technique with digital reduction, but sometimes a simple idea has sweet success.

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