

GUIDELINES

Identification and care pathways for common mental health disorders: summary of NICE guidance

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At any one time, as many as 15% of people in the United Kingdom¹ experience common mental health problems such as depression and anxiety disorders, including generalised anxiety disorder, panic disorder, post-traumatic stress disorder, and obsessive-compulsive disorder. These may cause considerable impairment and disability, with high costs for both the person and society. Most people who are diagnosed with a common mental health disorder (about 80%) are treated in primary care²; however, there is widespread under-recognition of depression and anxiety disorders.^{3 4}

This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) to improve identification of common mental health disorders, access to services, and pathways to care.⁵ The guideline also adopted or adapted treatment recommendations from existing NICE guidance on depression,^{6 7} generalised anxiety disorder and panic disorder,⁸ post-traumatic stress disorder,⁹ obsessive-compulsive disorder,¹⁰ and antenatal and postnatal mental health¹¹ and organised them into a common stepped care framework.

Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are in the full version of this article on bmj.com.

Identification of common mental health disorders

- Be alert to possible depression (particularly in people with a history of depression or a chronic physical health problem with associated functional impairment), and consider asking people who may have depression two questions, specifically:
 - During the past month, have you often been bothered by feeling down, depressed, or hopeless?
 - During the past month, have you often been bothered by having little interest or pleasure in doing things?

If a person answers "yes" to either of the above questions consider depression and follow the recommendations for assessment (see below).

- Be alert to possible anxiety disorders (particularly in people with a history of depression or those who have possible somatic symptoms of an anxiety disorder or have experienced a recent traumatic event). Consider asking the person about their feelings of anxiety and the ability to stop or control worry using the two item generalised anxiety disorder scale (GAD-2¹²) (box).

-If the person scores 3 or more on the GAD-2 scale, consider an anxiety disorder and follow the recommendations for assessment

-If the person scores less than 3 on the GAD-2 scale but you are still concerned they may have an anxiety disorder, ask: "Do you find yourself avoiding places or activities and does this cause you problems?" If the person answers "yes" consider an anxiety disorder and follow the recommendations for assessment (see below).

Assessment of common mental health disorders

- If the identification questions (above) indicate a possible common mental health disorder but you are not competent to perform a mental health

Generalised anxiety disorder scales (GAD-2¹² and GAD-7¹³)*

GAD-2 (short screening tool)

Over the past two weeks how often have you been bothered by the following problems:

- Feeling nervous, anxious, or on edge?
- Being unable to stop or control worrying?

GAD-7 (seven item)

This comprises the two questions above plus the following questions.

Over the past two weeks, how often have you been bothered by the following problems:

- Worrying too much about different things?
- Trouble relaxing?
- Being so restless that it is hard to sit still?
- Becoming easily annoyed or irritable?
- Feeling afraid as if something awful might happen?

*Scoring for both scales, for each question: not at all=0; several days=1; more than half the days=2; nearly every day=3

This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists. The supporting evidence statements and further information about the guidance are in the full version on bmj.com.

assessment, refer the person to an appropriate healthcare professional; if this professional is not the person's general practitioner, inform the general practitioner of the referral. If you are competent, however, to perform a mental health assessment, you should review the person's mental state and associated functional, interpersonal, and social difficulties.

- When assessing a person with a suspected common mental health disorder, consider using:
 - A diagnostic or problem identification tool or algorithm—for example, the screening prompts tool in the data handbook from the Improving Access to Psychological Therapies programme¹⁴
 - A validated measure relevant to the disorder or problem being assessed—for example, the nine item patient health questionnaire (PHQ-9),¹⁵ the hospital anxiety and depression scale (HADS),¹⁶ or the seven item generalised anxiety disorder scale (GAD-7)¹³ (box) to inform the assessment and support the evaluation of any intervention.
- As well as assessing symptoms and associated functional impairment, consider how the following factors may have affected the development, course, and severity of a person's presenting problem:
 - A history of any mental health disorder or chronic physical health problem
 - Any experience of and response to treatments

- The quality of interpersonal relationships
- Living conditions and social isolation
- A family history of mental illness
- A history of domestic violence or sexual abuse
- Employment and immigration status.

- If appropriate, assess the impact of the presenting problem on the care of children and young people and, if necessary, follow local safeguarding procedures.
- Always ask people about suicidal ideation and intent. If there is a risk of self harm or suicide:
 - Assess whether the person has adequate social support and is aware of sources of help
 - Arrange help appropriate to the level of risk
 - Advise the person to seek further help if the situation deteriorates.

Treatment and referral for treatment

- When discussing treatment options with a person with a common mental health disorder, consider:
 - Their past experience of the disorder and their experience of and response to previous treatment
 - The trajectory of symptoms
 - The diagnosis or problem specification and the severity and duration of the problem
 - The extent of any associated functional impairment arising from the disorder itself or any chronic physical health problem

Focus of intervention	Nature of intervention
<p>Step 3 Persistent subthreshold depressive symptoms or mild to moderate depression that has not responded to a low intensity intervention; initial presentation of moderate or severe depression; generalised anxiety disorder with marked functional impairment or that has not responded to a low intensity intervention; moderate to severe panic disorder; obsessive-compulsive disorder with moderate or severe functional impairment; post-traumatic stress disorder</p>	<p>Depression - Cognitive behavioural therapy, interpersonal therapy, behavioural activation, behavioural couples therapy, counselling,* short term psychodynamic psychotherapy,* antidepressants, combined interventions, collaborative care,† self help groups Generalised anxiety disorder - Cognitive behavioural therapy, applied relaxation, drug treatment, combined interventions, self help groups Panic disorder - Cognitive behavioural therapy, antidepressants, self help groups Obsessive-compulsive disorder - Cognitive behavioural therapy (including exposure and response prevention), antidepressants, combined interventions and case management, self help groups Post-traumatic stress disorder - Trauma focused cognitive behavioural therapy, eye movement desensitisation and reprocessing, drug treatment All disorders - Support groups, educational and employment support services; befriending, rehabilitation programmes; referral for further assessment and interventions</p>
<p>Step 2 Persistent subthreshold depressive symptoms or mild to moderate depression; generalised anxiety disorder; mild to moderate panic disorder; mild to moderate obsessive-compulsive disorder; post-traumatic stress disorder (including mild to moderate)</p>	<p>Depression - Individual facilitated self help, computerised cognitive behavioural therapy, structured physical activity, group based peer support (self help) programmes,† non-directive counselling delivered at home,‡ antidepressants, self help groups Generalised anxiety disorder and panic disorder - Individual non-facilitated and facilitated self help, psychoeducational groups, self help groups Obsessive-compulsive disorder - Individual or group cognitive behavioural therapy (including exposure and response prevention), self help groups Post-traumatic stress disorder - Trauma focused cognitive behavioural therapy or eye movement desensitisation and reprocessing All disorders - Support groups, educational and employment support services; referral for further assessment and interventions</p>
<p>Step 1 All disorders—known and suspected presentations of common mental health disorders</p>	<p>All disorders - Identification, assessment, psychoeducation, active monitoring; referral for further assessment and interventions</p>

* Discuss with the person the uncertainty of the effectiveness of counselling and psychodynamic psychotherapy in treating depression

† For people with depression and a chronic physical health problem

‡ For women during pregnancy or postnatally

Stepped care model for common mental health disorders, showing treatments that should be offered at each step and guidance on referral (for further details see the NICE guideline⁵)

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Previous articles in this series

- ▶ Diagnosis and treatment of lung cancer (*BMJ* 2011;342:d2110)
- ▶ Recognition and initial management of ovarian cancer (*BMJ* 2011;342:d2073)
- ▶ Inpatient management of diabetic foot problems (*BMJ* 2011;342:d1280)
- ▶ Assessment and management of psychosis with coexisting substance misuse (*BMJ* 2011;342:d1351)

- The presence of any social or personal factors that may have a role in the development or maintenance of the disorder
- The presence of any comorbid disorders.
- Provide information about:
 - The nature, content and duration of any proposed intervention
 - The acceptability and tolerability of any proposed intervention
 - Possible interactions with any current interventions
 - The implications for the continuing provision of any current interventions.
- If the person has:
 - Depression that is accompanied by symptoms of anxiety: the first priority should usually be to treat the depressive disorder, in line with the NICE guideline on depression⁶
 - An anxiety disorder and comorbid depression or depressive symptoms: consult the NICE guidelines for the relevant anxiety disorder⁸⁻¹⁰ and consider treating the anxiety disorder first
 - Both anxiety and depressive symptoms with functional impairment but no formal diagnosis: discuss with the person the symptoms to treat first and the choice of intervention
 - A common mental health disorder and harmful or dependent drinking: refer for treatment of the alcohol misuse^{17 18} first as this may significantly improve depressive or anxiety symptoms.
- When offering treatment for a common mental health disorder or making a referral, follow the stepped care approach, usually offering or referring for the least intrusive, most effective intervention first (figure).

Improving access to services and developing local care pathways

Primary and secondary care clinicians, managers, and commissioners should work together to develop local care pathways that promote access and care that are integrated across primary and secondary care services; access to services should be possible via various routes (including self referral) and entry points.

Ensure effective communication, with protocols for sharing information about patients' care (*a*) with service users and their families and carers where appropriate; (*b*) with other professionals (including general practitioners); and (*c*) with the services in the care pathway and services outside the pathway.

Overcoming barriers

Under-recognition of common mental disorders remains a problem,^{3 4} although use of the quality and outcomes framework (QOF) (a voluntary annual incentive programme for general practices in England to achieve specific results¹⁹) may improve the recognition and assessment of depression. Similar incentives for anxiety disorders do not exist, and their adoption might be considered to promote recognition. Developing effective and efficient local care pathways can improve the quality of care but requires

collaboration between professionals and managers in both primary and secondary care services.

Such collaboration needs to reach beyond healthcare professionals and traditional healthcare settings if it is to improve poor service access for some groups, such as older people and those from black and minority ethnic groups. This means working with a broad range of community based organisations in developing methods to improve access and settings in which to deliver services. The guideline provides clear advice about the criteria on which to base referrals for various psychological treatments, but access to such treatment remains limited,¹ and clinicians may be over-using medication, particularly in milder disorders. Thus the continued roll-out of programmes supporting evidence based psychological interventions, such as the Improving Access to Psychological Therapies programme (to train over 3000 new psychological therapists in the English NHS to provide such interventions in line with NICE guidance),^{20 21} will be important.

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- 1 McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R. *Adult psychiatric morbidity in England, 2007: results of a household survey*. NHS Information Centre for Health and Social Care, 2009.
- 2 Goldberg DP, Huxley PJ. *Common mental disorders: a bio-social model*. Tavistock/Routledge, 1992.
- 3 Kisely S, Gater R, Goldberg DP. Results from the Manchester Centre. In: Üstün TB, Sartorius N, eds. *Mental illness in general health care: an international study*. Wiley, 1995: 175-91.
- 4 Tylee A, Walters P. Underrecognition of anxiety and mood disorders in primary care: why does the problem exist and what can be done? *J Clin Psychiatry* 2007;68:27-30.
- 5 National Institute for Health and Clinical Excellence. Common mental health disorders: identification and pathways to care. 2011. (Clinical guideline CG123.) <http://guidance.nice.org.uk/CG123>.
- 6 National Institute for Health and Clinical Excellence. Depression: the treatment and management of depression in adults. 2009. (Clinical guideline 90.) <http://guidance.nice.org.uk/CG90>.
- 7 National Institute for Health and Clinical Excellence. Depression in adults with a chronic physical health problem: treatment and management. 2009. (Clinical guideline 91.) <http://guidance.nice.org.uk/CG91>.
- 8 National Institute for Health and Clinical Excellence. Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults: management in primary, secondary and community care. 2011. (Clinical guideline 113.) <http://guidance.nice.org.uk/CG113>.
- 9 National Institute for Health and Clinical Excellence. Post-traumatic stress disorder (PTSD): the management of PTSD in adults and children in primary and secondary care. 2005. (Clinical guideline 26.) <http://guidance.nice.org.uk/CG26>.
- 10 National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder: core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder. 2005. (Clinical guideline 31.) <http://guidance.nice.org.uk/CG31>.
- 11 National Institute for Health and Clinical Excellence. Antenatal and postnatal mental health: clinical management and service guidance. 2007. (Clinical guideline 45.) <http://guidance.nice.org.uk/CG45>.
- 12 Kroenke K, Spitzer RL, Williams JB, Monahan PO, Lowe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity and detection. *Ann Intern Med* 2007;146:317-25.

- 13 Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006;166:1092-7.
- 14 Improving Access to Psychological Therapies. The IAPT data handbook. 2010. www.iapt.nhs.uk/silo/files/the-iapt-data-handbook.pdf.
- 15 Spitzer R, Kroenke K, Williams J. Validation and utility of a self-report version of the PRIME-MD. The PHQ primary care study. *JAMA* 1999;282:1737-44.
- 16 Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* 1983;67:361-70.
- 17 National Institute for Health and Clinical Excellence. Alcohol-use disorders: diagnosis and clinical management of alcohol-related physical complications. 2010. (Clinical guideline 100.) <http://guidance.nice.org.uk/CG100>.
- 18 National Institute for Health and Clinical Excellence. Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. 2011. (Clinical guideline 115.) <http://guidance.nice.org.uk/CG115>.
- 19 Campbell SM, Reeves D, Kontopantelis E, Sibbald B, Roland M. Effects of pay for performance on the quality of primary care in England. *N Engl J Med* 2009;361:368-78.
- 20 Department of Health. Improving access to psychological therapies: specification for the commissioner-led pathfinder programme. Department of Health, 2007.
- 21 Clark DM, Layard R, Smithies R, Richards DA, Suckling R, Wright B. Improving access to psychological therapy: initial evaluation of two UK demonstration sites. *Behaviour Research and Therapy* 2009;47:910-20.

EASILY MISSED?

Giant cell arteritis

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This is one of a series of occasional articles highlighting conditions that may be more common than many doctors realise or may be missed at first presentation. The series advisers are Anthony Harnden, university lecturer in general practice, Department of Primary Health Care, University of Oxford, and Richard Lehman, general practitioner, Banbury. To suggest a topic for this series, please email us at easilymissed@bmj.com.

Giant cell arteritis affects large and medium sized arteries, often branches of the external carotid artery but also the ciliary and retinal arteries. The symptoms are caused by local ischaemia due to endovascular damage and cytokine mediated systemic illness. There is considerable overlap with polymyalgia rheumatica: 16-21% of patients with polymyalgia rheumatica have giant cell arteritis on temporal artery biopsy, and symptoms of polymyalgia rheumatica are present in 40-60% of patients with giant cell arteritis.¹

Why is giant cell arteritis missed?

A systematic review analysed the presenting clinical features in a mixture of studies with a total of 1435 cases of giant cell arteritis.³ The sensitivity of individual clinical features was relatively low (table), reflecting the diverse presentation of this condition: 24% of cases had no headache at all, and only 52% had a temporal headache. Giant cell arteritis can be easily missed when systemic symptoms (such as low grade fever or weight loss), ischaemic symptoms (jaw claudication or transient visual symptoms), or polymyalgic symptoms (proximal myalgia

CASE SCENARIO

A previously fit and well 72 year old man presented to his general practitioner after several months of malaise and weight loss. When asked about any pain, he pointed to his left scalp as being painful. Examination was normal except that his left temporal artery was not palpable. Suspecting giant cell arteritis, the GP started 40 mg prednisolone and requested an erythrocyte sedimentation rate, which was 86 mm/h. The symptoms largely disappeared in 48 hours. She also referred the patient for a temporal artery biopsy, which showed giant cell arteritis.

HOW COMMON IS IT?

- Giant cell arteritis occurs in 2.2 per 10 000 patient years in the United Kingdom²
- A full time general practitioner may expect to see one new case every 1-2 years
- It is virtually unknown in people aged under 50

or morning stiffness) predominate over the well known hallmark of temporal headache. The mean duration of symptoms in the 1435 patients at diagnosis was 3.5 months. A 1971 Swedish study examined 1097 consecutive autopsies with temporal artery examination carried out in each of them. Sixteen cases of undiagnosed giant cell arteritis were identified. Retrospective analysis of the case notes documented typical features of undiagnosed giant cell arteritis in 9.⁴ A recent audit of 65 patients with giant cell arteritis showed that 44 had had unrecognised visual disturbance, visual loss or stroke in the mean of 35 days between onset of symptoms and diagnosis (range of 2 to 336 days).⁵ Eleven of these patients presented without headache or scalp tenderness and 10 of these had visual loss.

Why does this matter?

Acute blindness occurs in up to 20% of patients with giant cell arteritis.⁴ Delay in recognition may explain the high

LEARNING POINTS

Giant cell arteritis is a medical emergency, as irreversible loss of vision can occur in 20% of cases without prompt treatment with steroids

"Typical" features such as headache and scalp tenderness may be absent, and this subgroup has a high risk of visual loss

Jaw or tongue claudication occurs in a minority of cases and heralds impending ischaemic complications
Erythrocyte sedimentation rate and C reactive protein are normal in only 4% of cases but may be just mildly raised in a fifth of cases

If giant cell arteritis is suspected, immediate treatment with high dose corticosteroids is indicated, and temporal biopsy should be arranged within two weeks of starting treatment

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Previous articles in this series

▶ Metastatic spinal cord compression
(*BMJ* 2011;342:d2402)

▶ Cholesteatoma
(*BMJ* 2011;342:d1088)

▶ Type 1 diabetes in children
(*BMJ* 2011;342:d294)

Sensitivity of clinical features in predicting giant cell arteritis³

Clinical feature	% of biopsy proven cases (sensitivity)
Headache:	
Any headache	76
Temporal headache	52
Scalp tenderness	31
Jaw claudication	34
Visual symptoms:	
Any visual symptom	37
Unilateral visual loss	24
Diplopia	9
Myalgia	39
Previous diagnosis of polymyalgia rheumatica	34
Weight loss	43
Fever	42
Temporal artery:	
Pulse absent	45
Any abnormality on palpation of temporal artery (absent, prominent, beaded)	65
Erythrocyte sedimentation rate:	
"Normal"	4
>50 mm/h	83

incidence of irreversible loss of vision, which is preventable with early diagnosis and treatment.⁴ Jaw or tongue claudication occurs in a minority of cases but heralds a high risk of impending ischaemic complications.⁶

How is giant cell arteritis diagnosed?

The typical presentation of giant cell arteritis is with temporal headache of recent onset, myalgia, or systemic malaise or fever, and the mean age of onset is 70. Erythrocyte sedimentation rate or C reactive protein is typically raised.² The case presented illustrates that "typical" features may be absent or subtle.

A meta-analysis looked at studies examining the value of individual clinical features in predicting positive results of temporal artery biopsy in patients with suspected giant cell arteritis.³ No clinical features had a high negative likelihood ratio, because no clinical feature (even headache) was reliably present in all cases. Several symptoms were moderately predictive of a positive biopsy result (likelihood ratio >2):

- Jaw claudication (present in 34% of cases); claudicant pain comes on gradually during chewing, whereas temperomandibular pain or dental pain is immediate
- Diplopia (present in 8% of cases)
- Any abnormality on palpation of the temporal artery—absent, beaded, tender, or enlarged (present in 65% of cases).

Other useful predictive features (likelihood ratio >1.5) were:

- Temporal headache
- Scalp tenderness
- Erythrocyte sedimentation rate >100 mm/h
- Anaemia.

The limitation of these studies is that giant cell arteritis was already highly likely, as all patients in the studied population had biopsies. In practice, the condition should be suspected in anyone over the age of 50 with headache, scalp tenderness, transient visual symptoms, or unexplained facial pain. Examination may show no abnormalities, but palpation of the temporal artery is often abnormal. Only 4% of patients have a completely "normal" erythrocyte sedimentation rate (half the age of the patient, plus 5 for women⁷); 83% have a rate above 50 mm/h. Once giant cell arteritis is suspected, refer patients urgently for temporal artery biopsy, which needs to be done within two weeks of starting steroids. The true sensitivity of temporal biopsy is not known, but one model estimates a sensitivity of 87%.⁸

How is giant cell arteritis managed?

Most treatment recommendations are based on experts' opinion, as randomised trials would be unethical.⁷ Once the diagnosis is suspected, treat with high dose corticosteroid immediately. Give 40 mg prednisolone daily unless the patient has ischaemic symptoms (jaw or tongue claudication, or visual symptoms). With claudication symptoms, give 60 mg prednisolone daily; if the patient has visual symptoms, admit for treatment with intravenous methylprednisolone.

Once symptoms and abnormal test results resolve, the dose can be reduced in 10 mg steps each two weeks to 20 mg, then in 2.5 mg steps. Most patients have stopped taking steroids by two years.⁹

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- 1 Salvarani C, Cantini F, Hunder GG. Polymyalgia rheumatica and giant-cell arteritis. *Lancet* 2008;372:234-45.
- 2 Smeeth L, Cook C, Hall AJ. Incidence of diagnosed polymyalgia rheumatica and temporal arteritis in the United Kingdom, 1990 to 2001. *Ann Rheum Dis* 2006;65:1093-8.
- 3 Smetana GW, Shmerling RH. Does this patient have temporal arteritis? *JAMA* 2002;287:92-101.
- 4 Ostberg G. Temporal arteritis in a large necropsy series. *Ann Rheum Dis* 1971;30:224-35.
- 5 Ezeonyeji AN, Borg FA, Dasgupta B. Delays in recognition and management of giant cell arteritis: results from a retrospective audit. *Clin Rheumatol* 2011;30:259-62.
- 6 Salvani C, Cimino L, Macchioni P, Consonni D, Cantini F, Bajocchi G, et al. Risk factors for visual loss in an Italian population-based cohort of patients with giant cell arteritis. *Arthritis Rheum* 2005;53:293-7.
- 7 Miller A, Green M, Robinson D. Simple rule for calculating normal erythrocyte sedimentation rate. *BMJ* 1983;286:266.
- 8 Niederkohr RD, Levin LA. A Bayesian analysis of the true sensitivity of a temporal artery biopsy. *Invest Ophthalmol Vis Sci* 2007;48:675-80.
- 9 Dasgupta B, Borg FA, Hassan N, Alexander L, Barraclough K, Bourke B, et al. BSR and BHPR guidelines for the management of giant cell arteritis. *Rheumatology* 2010;49:q039a.

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A PATIENT'S JOURNEY

Bilateral developmental dysplasia of the hips

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While training as a surgeon, **Sophie West** was diagnosed with bilateral developmental hip dysplasia. This is an account of her experience of the condition and of becoming a patient

I had just been offered a place on the London Deanery core surgical training programme, and was half way through completing my master's degree in sports and exercise medicine. I was also training for my first triathlon, having completed a duathlon the previous year. One night I woke up with groin pain. After checking myself repeatedly for hernias, I took some painkillers and managed to get back to sleep. The next morning I could hardly walk due to pain in my left hip and so hobbled around for the next couple of days, after which the pain improved and disappeared. I assumed I had pulled a muscle or something. I thought nothing more of it until it happened again about two weeks later, and then again, and again. After the fourth time I realised that something was not right and I got some radiographs done. A professor on my course reviewed the films and immediately told me I had hip dysplasia.

Despite having worked in orthopaedics during my second year as a junior doctor, I thought this condition was only seen in babies; my only experience had been when I performed the Ortolani and Barlow tests as part of new baby checks as a medical student. If it is missed in childhood, problems can develop later in life, but I still struggled to get my head round the fact I had this condition that was going to significantly affect my ability to walk. From the outset an osteotomy was mentioned, and I adamantly stated that no one was going to break my bones, let alone my pelvis . . . this was real denial!

Accepting the diagnosis and treatment

One of the benefits of working in the NHS was that I was able to bypass the usual referral routes and had access to several opinions from orthopaedic specialists. After the fourth surgeon had told me I needed a periacetabular osteotomy on my left hip—a surgical procedure in which the bones of the hip joint are cut, reorientated, and fixed in a new position—it started to dawn on me that this was the path I was going to have to take. During these months the pain had become a permanent feature and my right hip had also started to hurt, meaning that my mobility was becoming progressively impaired. In just a few months I had gone from running 20 kilometres a week to relying on crutches to walk and being in pain most of the time. The irony of the orthopaedic senior house officer being on crutches did not escape my patients either.

Knowing now that I was going to need two lots of major surgery, each with prolonged recovery and rehabilitation periods, and potentially lifelong problems with my hips, left me in a state of despair. I felt that my life was turning upside down. By this time I had started working at the hospital where I was going to be treated, and despite having lots of col-

leagues to talk to about the condition and the operations, no one could tell me what it was like to have a pelvic osteotomy and how it was going to affect my life—I felt very alone.

Finding support

I discovered a charity, Steps, of which I have since become a trustee. Through their family contacts, they put me in touch with other people with developmental dysplasia of the hips. It was such a relief to be able to talk at last to someone who understood exactly how scared I was, what it was like living in pain, and who could answer some of my questions about surgery and recovery. One of the things that struck me talking to fellow patients was the length of time and number of visits to different specialists many people had been through to get an accurate diagnosis. Although this did not surprise me (having not known about it myself) it highlighted for me the importance of recognising the causes of hip pain in young adults.

Being a patient

Most people are apprehensive about being patients, but as a surgical trainee I had insight into what I was really letting myself in for, especially when I ended up having to assist my surgeon doing the operation on someone else. A periacetabular osteotomy involves the bones around the hip socket being broken and then realigned to give better coverage of the femoral head, restoring the biomechanics of the joint to nearly normal in the process, and reducing the risk of secondary arthritis—joint preservation surgery. I was relieved to have this option available to me; the thought of a total hip replacement at the age of 27 years was a frightening prospect, and until recently that was the only option available to people in my situation.

I am lucky, I have a supportive husband and family. We quickly realised that this was something we were all going to go through together. After the operations I was not going to be able to look after myself, which meant moving out of the flat I share with my husband and staying with my parents over 70 miles away. After each operation I was unable to put any weight through my hip for six weeks and then I gradually built up to walking with no crutches over the subsequent four weeks. I also used a wheelchair to go out of the house as it was too tiring and painful to walk with crutches all the time. The hardest thing was after the first periacetabular osteotomy, knowing that however much pain I was in, I was going to have to go through it all again with the right hip.

I felt extremely vulnerable as a patient, and the complete loss of independence was something I could not have prepared for. Relying on others to help you complete the most basic of daily tasks (washing, dressing), initially from colleagues at work and then from my husband and parents, was a revelation to say the least, and it has given me insight into being a patient that I could never have appreciated before.

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.

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- ▶ Motor neurone disease (*BMJ* 2011;342:d1661)
- ▶ Through the wasteland: chronic depression (*BMJ* 2011;342:d93)
- ▶ Adult atopic eczema (*BMJ* 2011;342:d644)
- ▶ Alcoholism (*BMJ* 2011;342:d956)

A DOCTOR'S PERSPECTIVE

Hip dysplasia is a condition in which the acetabulum is too shallow and does not effectively cover enough of the femoral head. About 80% of cases occur in female patients. The consequence is that weight bearing stress is concentrated over a small area of the articular surface, and this initially causes damage at the junction of the acetabular labrum (the ring of cartilage that surrounds the acetabulum) with the articular cartilage. If this abnormal stress continues in this area, it can result in the breakdown of the articular cartilage and in turn osteoarthritis.

Hip dysplasia is a common cause of osteoarthritis of the hip in patients aged between 50 and 80 years. About 80% of patients coming in for hip replacement surgery have a biomechanical abnormality of the hip, which leads to the development of osteoarthritis; in women, the commonest abnormality is hip dysplasia. This trend in women suggests that earlier in life a lot of these patients may well have had unrecognised symptoms. Hip symptoms caused by dysplasia commonly present as pain in the groin region that are associated with activity. For example, symptoms may initially begin after a sporting activity, but as damage to the labrum progresses, pain becomes more persistent and can be very severe, sometimes necessitating the use of crutches.

The diagnosis of this condition relies largely on the awareness that recurrent groin pain associated with activity in a young individual is not normal and requires further investigation. The diagnosis can usually be made with plain radiographs, but these require correct interpretation—for example, subtle dysplasia where the deficiency is largely anterior can easily be missed by a radiograph. MRI scans by themselves can be misleading, in that labral tears are very common in the presence of dysplasia because this is where

the initial lesion develops. Although this may be diagnosed on MRI, dysplasia leading to the tear will not necessarily be recognised.

Once patients show symptoms, this is an indication that the hip is starting to decompensate with damage occurring at the capsulo-labral complex. Treatment is largely based around correcting the underlying structural abnormality of the hip. This type of surgery is suitable for patients in whom the femoral head is not too deformed and where arthritic damage has not progressed too far, hence the importance of early recognition.

Periacetabular osteotomy is the procedure of choice to correct the bony abnormality. The surgery involves rotating the acetabulum into a new position after making bony cuts to free it from the pelvis. The acetabular fragment is then held in the new position by screws. This allows the patient to mobilise and start rehabilitation without the need for external splints. For the patient, the idea of such a procedure can be quite daunting because it is clearly a major intervention. An advantage of increased subspecialisation in surgery is that procedures such as this can now be performed safely and effectively with good reproducibility in terms of outcome. This type of surgery can also be performed through a small, cosmetically acceptable incision (8-10 cm), which is an important consideration for young patients.

Recovery after surgery is related to psychological factors surrounding the procedure itself and patients' perception of how they will be during and after surgery. Identifying these factors before surgery is extremely important so that they can be addressed. We have found that a patient focus group has been very helpful in identifying factors that can clearly influence recovery.

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It was an eye opening experience using a wheelchair, seeing how differently people treat you, and just how hard getting around in one can be.

Bridging the gap

Most orthopaedic surgeons carry out thousands of procedures in their career, while very few will need one of these procedures done themselves. I wanted to be able to use my experience to bridge this gap of knowledge. Along with my surgeon, we arranged a focus group including anaesthetists,

pre-assessment nurses, physiotherapists, and occupational therapists. We invited five patients who had undergone a periacetabular osteotomy, including myself, to share their ideas, concerns, and experiences. The most interesting outcome was the difference between what the medical team thought would be the most discussed topics (such as pain and hospital stay), and what the patients actually felt were the most important factors (such as information before and after the operation and the rehabilitation period). This experience has shown me that as physicians, while we think we know how patients may feel and what they are worried about, we really don't. The experience of the focus group was valued by everyone involved and has led to changes and better provision of information for patients. A patient focus group with a multi-disciplinary team input is an excellent way to understand our patients and the conditions we treat.

Looking forward

Although I still have one small operation on my right hip to come, I am now getting on with my life with the knowledge that my hips still have plenty of years left in them. I am enjoying working and finally getting on with my training, and have even entered a triathlon for next year. It will be three years since I last signed up to one, but I know the achievement now is going to be so much greater.

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FURTHER READING

Steps charity (www.steps-charity.org)—National UK based charity that provides support and information for patients and their families with lower limb conditions, including developmental dysplasia of the hips. "We don't take walking for granted"

The International Hip Dysplasia Institute (www.hipdysplasia.org)—International group with the mission to reduce the physical, social, and economic burden for children and adults affected by neonatal hip instability and hip dysplasia. They provide information for patients and medical professionals and conduct important research into the condition

Hip Surgery (www.hipjointsurgery.co.uk)—Website providing information on hip dysplasia, hip arthroscopy, femoroacetabular impingement, periacetabular osteotomy, and total hip replacement. Developed by Johan Witt (co-author of this article), an orthopaedic surgeon specialising in hip conditions in young people