GUIDELINES

Management of acute upper gastrointestinal bleeding: summary of NICE guidance

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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.

Further information about the guidance, a list of members of the guideline development group, and the supporting evidence statements are in the full version on bmj.com.

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Previous articles in this series

- Prescribing strong opioids for pain in adult palliative care (*BMJ* 2012;344:e2806)
- Improving the experience of care for people using NHS services (*BMJ* 2012;344:d6422)
- Improving the experience of care for adults using NHS mental health services (*BMJ* 2012;344:e1089)
- Diagnosis and management of the epilepsies in adults and children (*BMJ* 2012;344:e281)

Acute upper gastrointestinal bleeding is the commonest medical emergency managed by gastroenterologists in the United Kingdom. The most frequently identified source of bleeding is peptic ulcer disease, but other important causes exist, particularly oesophageal or gastric varices, which are classically associated with more severe bleeding. A large audit in the UK in 2007[1] indicated that the rate of mortality from acute upper gastrointestinal bleeding (about 7%) has not changed much over the past 50 years, and that service provision varies considerably across the UK. This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) on the management of acute upper gastrointestinal bleeding.[2]

Recommendations

NICE recommendations are based on systematic reviews of the 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.

Table 1 | The Blatchford scoring system.[3] For a patient with acute upper gastrointestinal bleeding, add up scores in the right hand column for each risk marker (if no value applies for a particular marker, score 0) to derive a total score*

Risk marker at admission	Score
Blood urea (mmol/L)	
≥6.5 <8.0	2
≥8.0 <10.0	3
≥10.0 <25	4
≥25	6
Haemoglobin (g/L) for men	
≥120 <130	1
≥100 <120	3
<100	6
Haemoglobin (g/L) for woman	
≥100 <120	1
<100	6
Systolic blood pressure (mm Hg)	
100-109	1
90-99	2
<90	3
Other markers	
Pulse ≥100 (beats/min)	1
Presentation with malaena	1
Presentation with syncope	2
Hepatic disease	2
Cardiac failure	2

*A total score can range from 0 to 23. A score of 0 is the clinical cut-off, above which patients are considered to be at risk of needing an intervention.

Risk assessment

At presentation with acute upper gastrointestinal bleeding, assess for risk of serious adverse events or need for intervention. To do this use the following formal risk assessment scoring systems for all patients with acute gastrointestinal bleeding: the Blatchford scoring system[3] at first assessment and the full Rockall scoring system[4] after endoscopy (tables 1 and 2)

Resuscitation and initial management

Patients with massive bleeding

- Transfuse with blood, platelets, and clotting factors in line with local protocols for managing massive bleeding.

Blood products

- Base decisions on blood transfusion on the full clinical picture, recognising that overtransfusion may be as damaging as undertransfusion.
- Do not offer platelet transfusion to patients who are not actively bleeding and who are haemodynamically stable.
- Offer platelet transfusion to patients who are actively bleeding and have a platelet count of $<50\times10^9$/L.
- Offer fresh frozen plasma to patients who have *(a)* a fibrinogen concentration <1 g/L or *(b)* a prothrombin time (international normalised ratio) or activated partial thromboplastin time that is more than 1.5 times the normal level.
- Do not use recombinant factor VIIa except when all other methods have failed.

Patients who are taking warfarin

- Offer prothrombin complex concentrate to patients who are taking warfarin and are actively bleeding.
- Treat patients who are taking warfarin and whose upper gastrointestinal bleeding has stopped in line with local warfarin protocols.

Timing of endoscopy

- Offer endoscopy to unstable patients with severe acute upper gastrointestinal bleeding immediately after resuscitation.
- Offer endoscopy within 24 hours of admission to all other patients with upper gastrointestinal bleeding.
- Units seeing more than 330 cases a year should offer daily endoscopy lists; units seeing fewer than this should arrange their service according to local circumstances.

Table 2 | The full (post-endoscopy) Rockall scoring system.[4] For a patient with acute upper gastrointestinal bleeding, add up scores at the top of the columns for each of the variables to derive a total risk score*

	Score*			
	0	1	2	3
Age†	<60	60-79	≥80	
Shock†	No shock (systolic blood pressure ≥100, pulse <100)	Tachycardia (systolic blood pressure ≥100, pulse ≥100)	Hypotension (systolic blood pressure <100)	
Comorbidity†	No major comorbidity		Cardiac failure, ischaemic heart disease, any major comorbidity	Renal failure, liver failure, disseminated malignancy
Diagnosis‡	Mallory-Weiss tear, no lesion identified, and no stigmata of recent haemorrhage	All other diagnoses	Malignancy of upper gastrointestinal tract	
Major stigmata of recent haemorrhage‡	None or dark spot only		Blood in upper gastrointestinal tract, adherent clot, visible or spurting vessel	

*The total score can range from 0 to 11, with a score of 2 representing the clinical cut-off, above which patients are considered to be at high risk of death or rebleeding.
†Scores are calculated on admission.
‡Scores are added after endoscopy.

Management of non-variceal bleeding

Proton pump inhibitors

- Do not offer acid suppression drugs (proton pump inhibitors or H_2 receptor antagonists) before endoscopy to patients with suspected non-variceal upper gastrointestinal bleeding.
- Offer proton pump inhibitors to patients with non-variceal upper gastrointestinal bleeding and stigmata of recent haemorrhage shown at endoscopy.

Endoscopic treatment

- Do not use adrenaline as monotherapy for the endoscopic treatment of non-variceal upper gastrointestinal bleeding.
- For the endoscopic treatment of non-variceal upper gastrointestinal bleeding, use one of the following:
  - A mechanical method—for example, clips with or without adrenaline
  - Thermal coagulation with adrenaline
  - Fibrin or thrombin with adrenaline.

Unstable patients who rebleed after endoscopic treatment

- Offer interventional radiology; if this is not promptly available, refer urgently for surgery.

Management of variceal upper gastrointestinal bleeding

Terlipressin

- Offer terlipressin, a vasopressin analogue, to patients with suspected variceal bleeding at presentation. Stop treatment after definitive haemostasis has been achieved or after five days, unless there is another indication for its use, such as renal failure. At the time of publication (June 2012), terlipressin was indicated for the treatment of bleeding from oesophageal varices, with a maximum duration of treatment of 72 hours. Prescribers should consult the relevant summary of product characteristics and obtain and document informed consent for off-label use.

Antibiotics

- Offer prophylactic antibiotic treatment at presentation to patients with suspected or confirmed variceal bleeding.

Oesophageal varices

- Use band ligation in patients with bleeding from oesophageal varices.
- Consider using transjugular intrahepatic portosystemic shunts if oesophageal variceal bleeding is not controlled by band ligation.

Gastric varices

- Offer endoscopic injection of N-butyl-2-cyanoacrylate to patients with bleeding from gastric varices.
- Offer transjugular intrahepatic portosystemic shunts if bleeding from gastric varices is not controlled by endoscopic injection of N-butyl-2-cyanoacrylate.

Primary prophylaxis in acutely ill patients

- Offer acid suppression treatment (H_2 receptor antagonists or proton pump inhibitors) for primary prevention of upper gastrointestinal bleeding in acutely ill patients admitted to critical care. If possible, use the oral form of the drug.
- Review the ongoing need for acid suppression drugs for primary prevention of upper gastrointestinal bleeding in acutely ill patients when they recover or are discharged from critical care.

Control of bleeding and prevention of re-bleeding in patients taking NSAIDS, aspirin, or clopidogrel

A substantial proportion of acute peptic ulcer bleeds occur in patients taking non-steroidal anti-inflammatory drugs (NSAIDs), aspirin, or clopidogrel. In patients with upper gastrointestinal bleeding who are taking these drugs:

- Continue low dose aspirin for secondary prevention of vascular events once haemostasis has been achieved.
- Stop other non-steroidal anti-inflammatory drugs (including cyclo-oxygenase-2 inhibitors) during the acute phase of bleeding.
- Discuss the risks and benefits of continuing clopidogrel (or any other thienopyridine antiplatelet agents) with the appropriate specialist (for example, a cardiologist or a stroke specialist) and with the patient.

Overcoming barriers

Some recommendations in this guideline may pose difficulties for some services, in particular doing endoscopy within 24 hours for any patient presenting with acute gastrointestinal bleeding (sooner if the patient is unstable).

The health economic model devised to inform this recommendation showed that, for units treating a large number of acute upper gastrointestinal bleeds annually, it was highly likely that providing daily endoscopy lists would reduce length of the hospital stay and that this reduction would offset the cost of additional staffing for weekend lists. The cost effectiveness of weekend lists in smaller units is less certain, and this strategy of providing endoscopy could not be firmly recommended in smaller units on health economic grounds. The GDG therefore stipulated that all patients should receive endoscopy within 24 hours without specifying how smaller units should achieve this; the possibility of network arrangements may offer one potential mechanism for smaller providers.

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EASILY MISSED?

Herpes simplex encephalitis

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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

The wife of a previously healthy 40 year old man requested a domiciliary visit from their general practitioner for her husband, who had been in bed for a few days with "bad flu," fever, and headache. She was worried that he was becoming quite confused and unable to recall recent events. The GP finds the patient is febrile, agitated, and disoriented in time and place. Concerned about encephalitis, he sends the patient immediately to hospital. There a CT scan shows an area of decreased attenuation in the right temporal lobe and a lumbar puncture a raised lymphocyte count, both suggesting herpes simplex encephalitis. Aciclovir treatment is immediately started.

What is herpes simplex encephalitis?

Herpes simplex encephalitis is a severe viral infection of the central nervous system that is usually localised to the temporal and frontal lobes in adults. Typically, it causes a flu-like illness with headache and fever followed by seizures, cognitive impairment, behavioural changes, and focal neurological signs, but its presentation is variable.

Why is it missed?

The clinical presentations of herpes simplex encephalitis are varied. The viral prodrome may be absent, and the cognitive impairment may be subtle. Focal neurological features can be mistaken for stroke, seizures for primary epilepsy, cognitive impairment for non-specific delirium, and behavioural changes for a primary psychiatric disorder. Clinicians may be reluctant to perform invasive testing unless viral encephalitis is strongly suspected. A recent analysis of 16 cases presenting between 1993 and 2005 showed that there were often substantial delays in performing examinations of cerebrospinal fluid.[5] Even when investigations are performed early in the course of the disease, results may be misleadingly negative: cerebrospinal fluid cell count is normal in 5–10% of patients, particularly in children; computed tomography results are normal in the first week of illness in up to a third of patients; magnetic resonance images are normal in 10%; and detection of viral DNA by the polymerase chain reaction can be negative initially.[6 3]

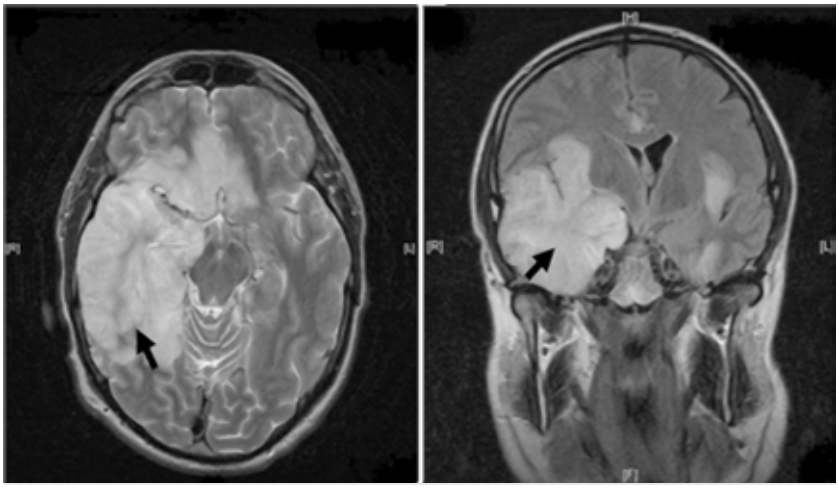
HOW COMMON IS HERPES SIMPLEX ENCEPHALITIS?

- Herpes simplex was the most commonly identified cause of infectious encephalitis in a large prospective UK study[1]
- It accounts for 5–10% of all cases of encephalitis worldwide[2]
- The annual incidence of herpes simplex encephalitis is 0.2–0.4/100 000 in the general population[3]
- It affects either sex, with no seasonal variation[1]
- It affects all age groups but is most common and severe in children and elderly people.[4] About 33% of patients are aged less than 20 years, and 50% are over 50 years at presentation
- Of the two types of herpes simplex virus (HSV-1 and HSV-2), HSV-1 encephalitis is more common in adults, and HSV-2 infection is more common in neonates[2]
- Other herpes viruses that cause encephalitis include varicella zoster virus, Epstein-Barr virus, cytomegalovirus, and human herpes viruses 6 and 7

Why does this matter?

Herpes simplex encephalitis is uncommon but has high mortality and morbidity if treatment with aciclovir is not given or delayed. Aciclovir inhibits viral replication and prevents extension of the disease within the brain, thereby reducing mortality from more than 70% in untreated patients to 19%.[4] The most common result of delayed treatment is neuropsychological impairment, with amnesia because of selective involvement of the limbic system.

In the well known case of the celebrated pianist and conductor Clive Wearing, diagnosis was delayed for five



Axial and coronal T2 weighted magnetic resonance images showing areas of hyperintensity (arrowed) corresponding to oedematous changes in the temporal lobes and inferior frontal lobes with mass-like effect due to herpes simplex virus encephalitis. Reproduced with permission of Southampton General Hospital's picture library

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Previous articles in this series

- Familial hypercholesterolaemia (*BMJ* 2012;344:e3228)
- Late onset type 1 diabetes (*BMJ* 2012;344:e2827)
- Acute Charcot foot (*BMJ* 2012;344:e1397)
- Phaeochromocytoma (*BMJ* 2012;344:e1042)
- Multiple myeloma (*BMJ* 2012;344:d7953)

days, and he survived with permanent and profound anterograde amnesia.[7] Several costly medicolegal claims have resulted from similar delays in diagnosis.[5]

How is herpes simplex encephalitis diagnosed?

Clinical features

There is usually a prodrome of malaise, fever (90%), headache (81%), and nausea and vomiting (46%) lasting for a few days, consistent with a viral infection.[8] On this background, features raising suspicion of encephalitis include the concurrent onset of:[8]

- Progressive alterations of behaviour (71%)
- Features suggestive of focal epilepsy (67%), such as olfactory hallucinations or periods of altered awareness
- Focal neurological signs (33%), such as unilateral weakness
- Cognitive problems (24%), such as difficulty in word finding, memory impairment, or confusion.

Investigations

If herpes simplex encephalitis is suspected, brain imaging (magnetic resonance imaging if possible, otherwise computed tomography) and cerebrospinal fluid analysis (if lumbar puncture is not contraindicated, such as by mass effect or coagulopathy) should be performed urgently.[3] Magnetic resonance imaging is the imaging modality of choice, and is abnormal in 90% of patients (figure).[2] Brain imaging both helps to support the diagnosis of herpes simplex encephalitis and to exclude contraindications to lumbar puncture. It typically shows unilateral or asymmetric bilateral high signal in the medial temporal lobes, insular cortex, and orbital surface of the frontal lobes (best seen with fluid attenuated inversion recovery (FLAIR) and diffusion weighted imaging (DWI)). These changes are not specific for herpes simplex. The differential diagnosis includes other causes of limbic encephalitis (such as paraneoplastic or autoimmune limbic encephalitis),[9] gliomatosis cerebri (a rare primary brain tumour), middle cerebral artery ischaemia, and possibly the effects of status epilepticus.

KEY POINTS

- Herpes simplex encephalitis is highly treatable, but can cause death or severe neuropsychological impairment if untreated
- The diagnosis is suggested by acute or subacute onset of
  - Alterations of behaviour
  - Focal or generalised seizures
  - Focal neurological signs
  - Cognitive difficulties
  - Usually on a background of fever and headache
- If it is suspected perform urgent brain imaging (preferably magnetic resonance imaging) and cerebrospinal fluid analysis for microscopy and DNA testing (if lumbar puncture is not contraindicated), bearing in mind that these may be normal early in the course of the disease
- Start intravenous aciclovir immediately if the diagnosis is suspected

The cerebrospinal fluid typically shows a raised lymphocyte count (10–500×10^6/L, average 100×10^6/L), sometimes with red blood cells with or without xanthochromia, reflecting the haemorrhagic nature of the encephalitis, mildly raised protein levels, and normal or mildly decreased glucose. Definitive diagnosis of herpes simplex encephalitis is made by the detection of viral nucleic acid in the cerebrospinal fluid by the polymerase chain reaction. This test has a sensitivity of 96–98% and specificity of 95–99% and has removed the need for brain biopsy.[2] It remains positive for at least five to seven days after starting antiviral therapy.[6] Viral DNA may be undetectable in early disease, but, if so, a repeat examination by polymerase chain reaction on cerebrospinal fluid three to seven days later can clinch the diagnosis.[2]

Electroencephalography has a high sensitivity (84%) but low specificity (32%) for the diagnosis of herpes simplex encephalitis.[9] However, it can be helpful in identifying non-convulsive seizure activity, which will benefit from anticonvulsant treatment.

How is herpes simplex encephalitis managed?

Pending the confirmation of the diagnosis of herpes simplex encephalitis, all adults with suspected encephalitis should be given aciclovir empirically, at a dose of 10 mg/kg, administered as intravenous infusions over one hour and repeated every eight hours for 14-21 days if renal function is normal.[2 3] Higher doses are recommended for immunocompromised patients. If bacterial meningitis is considered a possibility, appropriate antibacterial therapy should also be given.[2] Should seizures occur, they are treated with anticonvulsants along standard lines. Raised intracranial pressure will occasionally require treatment. The role of adjunctive corticosteroids is not yet established.

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A PATIENT'S JOURNEY

Herpes simplex virus encephalitis

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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.

Darren Egdell developed herpes simplex virus encephalitis 10 years ago, aged 31. He and his father, Raymond, look back at the initial illness and describe his remarkable progress

Raymond—the patient's father

When Darren first became ill, the doctor diagnosed flu; and all the symptoms pointed to flu. It was only two days later, when he woke one morning mumbling and incomprehensible, that his mum and I realised there was more to it than flu. We phoned an ambulance straight away.

A young doctor rushed into the accident and emergency department, and I feared the worst. He said it was either meningitis, a growth on the brain, or encephalitis. I didn't want to think about meningitis or a growth on the brain, and I'd never heard of encephalitis before, so I told him that if I could choose, I would have that. But he told me that was the last one I should pick, because it was the worst. Fortunately it didn't take long for the doctors to reach a diagnosis and start the treatment with aciclovir. They saved Darren's life. Without a diagnosis and treatment at that point, they would not have been able to do anything for him.

He was in hospital for about six weeks. We were there all day, every day. But it was hard. For a couple of weeks we didn't know whether he would survive or not; but even when he did, nobody told us what sort of person we would be taking home from the hospital. When he came round, he didn't know who we were. And bizarrely, he couldn't speak any English at first, only French. He had done French at university and spoken it fluently. But his mum and I don't speak French so it was impossible to converse with him. We had to have a translator to talk to our own son. He had a terrible temper and argumentative side to begin with; and he swore, which he had never done before. It wasn't Darren that we had brought home; it was a different person. He had been allowed home for a weekend, and didn't know where he was. At the end of the weekend, when it was time to go back to the hospital, he very politely thanked me and his mum for having him. It was heartbreaking at the time.

Each day in hospital the specialist would come and see him, and ask him to name things in English. Darren could describe how a fountain pen worked in minute detail, and what it was for; but he couldn't actually tell you what it was called. The doctor would ask him who the prime minister was. Hour after hour I would drum it into him "Tony Blair, Tony Blair." But he still couldn't remember. He had to relearn everything. He didn't know simple words such as knife, fork, or spoon. First we played easy word games with him then moved on to Scrabble. He played again and again and again, until he could beat us both, as before. But to this day he still can't remember the names of animals.

I had been so proud of how bright Darren was before his illness. He was a member of MENSA and had his French degree and a high powered job. Then to see it all disappear in a matter of a few days was unbelievable—to know his brain is never going to be the same again, that he's never going to be able to use it the way he did. All gone. That's very hard to accept. But he has done so well, worked so hard, to get this far. I am proud of him for that. Over the years he has got rid of the temper and got back to being the lovely person he was. When I compare him with others we meet through the Encephalitis Society, I realise how much he has improved.

The Encephalitis Society has been a real lifesaver for us. We go for trips, and it is clear some people have been affected even more than Darren. Four of them went to McDonald's; they put their order in, but by the time the food came, only two minutes later, no one could remember what they'd asked for. He goes on holiday with one friend from the society. They went to France in the car. Darren can remember the names of places, but she can't. She can remember the routes, but he can't. So between them they get there.

Darren

I don't remember much about being ill. I can remember going to my girlfriend's house for something to eat, but it was weird; the food smelt disgusting and made me sick. I went to bed on the Saturday night feeling tired, and with a headache. On the Sunday when I woke my speech wasn't making sense. I thought I was talking normally, but I wasn't. I couldn't understand why everyone was looking at me strangely.

A DOCTOR'S PERSPECTIVE

Herpes simplex virus encephalitis is the most commonly diagnosed viral encephalitis in the United Kingdom, with an annual incidence estimated at 2-4 per million. Although in the 1980s the mortality improved with the introduction of aciclovir, the morbidity remains high, especially when treatment is started late. Recent work by our group, and others, looking at where the delays occur and why, has resulted in the development of new national encephalitis guidelines (see "Useful resources" box), which should encourage better management.

In Darren's case there were no delays in treatment. He was admitted to hospital on the day he developed altered consciousness; in retrospect, the apparently disgusting smell of food was probably an olfactory hallucination, which may be an early clue to herpes encephalitis. In hospital the constellation of a febrile illness and abnormal behaviour was quickly recognised as an indicator of possible brain infection; the lumbar puncture was consistent with viral disease, and aciclovir was started, all within a few hours of admission. However, Darren's outcome shows that despite rapid treatment, the effect of herpes simplex virus on the brain can still be catastrophic, both for the patient and the family. The importance of the Encephalitis Society in helping Darren and his family to cope with the illness is also very apparent.

Herpes simplex virus type 1 is transmitted through droplets and is thought to enter the central nervous system via the olfactory nerve, which sends branches to the temporal lobes, hence the characteristic damage to this part of the brain in herpes encephalitis. The medial temporal lobe, especially the hippocampus, is important in laying down new memories (anterograde memory); this explains why anterograde memory is so often affected in herpes encephalitis. In Darren's case, in addition to anterograde amnesia, there is memory loss for events before the illness—retrograde amnesia. His knowledge of facts, semantic memory, is also affected, with a striking inability to recall the names of common objects. Perhaps most extraordinary of all, though, is that despite his difficulties with English, Darren's French language skills were relatively preserved. Whereas verbal memory is strongly left lateralised in the medial temporal lobe, learning of foreign language is thought to reside in the right hemisphere; and clearly in Darren's case this has made an enormous difference to the sequelae of his disease.

But beyond the fascinating insights it gives us into how the brain works, this case highlights the need for further research on disease mechanisms in encephalitis, and the role of anti-inflammatory treatments as adjuncts to antiviral drugs.

Tom Solomon, professor of neurological science

USEFUL RESOURCES

- Encephalitis Society (www.encephalitis.info/)—Offers support for those affected by encephalitis, raises awareness, and promotes research
- Solomon T, Michael BD, Smith PE, Sanderson F, Davies NWS, Hart IJ, et al. Management of suspected viral encephalitis in adults—Association of British Neurologists and British Infection Association National Guidelines. *J Infection* 2012;64:347-73
- Kneen R, Michael BD, Menson E, Mehta B, Easton A, Hemingway C, et al. Management of suspected viral encephalitis in children—Association of British Neurologists and British Paediatric Allergy, Immunology and Infection Group National Guidelines. *J Infect* 2012;64:449-77
- www.braininfectionsuk.org/—A portfolio of research studies aimed at improving the outcome of encephalitis and other central nervous system infections of major importance in the UK
- Liverpool Neurological Infections Diseases Course (www.liv.ac.uk/neuroidcourse/)—An annual course for clinicians of all specialties who want to update their knowledge and improve their skills

When I was recovering, the doctors would always ask me the same questions. They wanted to know who the prime minister was. Once, I gave them a perfect description: a woman, blond, pearl necklace, always wears blue, and carries a handbag. And the doctors laughed because apparently I'd given a perfect description of the prime minister, but the wrong one. She had been replaced 10 years earlier. They would show me pictures, but I couldn't name the objects. Some I still struggle with—for example, the thing you get near the North Pole; it's made of ice; like a circle; it has a door on it; you can go inside; all the blocks of ice are put together; it has to be cold there, otherwise the ice melts. I can tell you all about it, but can never remember what it is called.

I watch French DVDs with English subtitles, to help me learn the English words again; then I watch the film again in English, and see if I can understand it. I read books in French, especially kids' books. I like the Roald Dahl and Harry Potter books. Unlike adult books, children's keep repeating the same words, again and again. This helps you remember them. But I struggle with names. For example, I can remember Harry Potter, and Ron Weasley; but I can never remember the name of the girl. Even though I know it starts with H and has eight letters.

I have little ways of trying to remember names. My next door neighbour, for example, is a bit shorter than me; so instead of Darren, his name is shorter—Dan. Sometimes if I can't remember an English word, I'll think of the French, and that helps me get there. It can be embarrassing in a supermarket. I am looking for something and can't find it; then by the time I've got the attention of the staff, I've forgotten the name of the thing I am looking for.

Moving into my current house, with three floors, was difficult at first. I'd be in the kitchen and need something from the top floor. By the time I got there I'd have forgotten what I wanted. That happens to everyone. But I'd then get back down to the kitchen, realise what I needed, and go up and down, three or four times, until in the end, I learnt to write a Post-it note, and stick it on the back of my hand, so I know what I am looking for. I dictate into a Dictaphone to keep a diary of what needs doing, and I leave notes everywhere. And I have to keep everything organised in exactly the right place, otherwise I can never find things.

The Encephalitis Society has a retreat every two years in Wales, which is the most brilliant thing. It is for people who have had encephalitis, so it is not embarrassing. The first time I went there I met a man who said "my memory is not that bad; I know your name is Darren and you are from the north west." But at dinner time, he kept asking for more and more soup, because he couldn't remember he had just had some! It is weird; everyone has different memory problems. One man went to the toilet, and got lost on his way back; he ended up knocking on the window. I was in hysterics. It was so great to meet others who have similar problems.

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QUALITY IMPROVEMENT REPORT

Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure

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Problem Transition from paediatric to adult care of young adults with chronic diseases is poorly coordinated, often delayed, and usually managed through a single referral letter. About 35% of young adults lose a successfully functioning kidney transplant within 36 months of transfer from paediatric to adult services.

Design Before and after study of the impact of a new integrated paediatric-adult clinical service for patients with kidney failure.

Setting Adult renal centre in Oxford and two paediatric renal centres in London.

Strategies for change An integrated paediatric-young adult joint transition clinic and care pathway was established in 2006, in conjunction with a young adult clinical service with regular community based clinics. Previously, young adult transplant recipients were transferred by a single referral letter to an adult renal consultant and managed in a conventional adult clinic.

Key measures for improvement Rates of acute rejection and loss of kidney transplants five years before and five years after the introduction of the integrated young adult care pathway.

Effects of the change Nine young adult kidney transplant recipients were transferred directly to adult care between 2000 and 2006 (group 1). From 2006 to 2010, 12 young adult transplant recipients underwent integrated transition into the new young adult service (group 2). Six transplants were lost in group 1 (67%) compared with no transplant losses in group 2.

Lessons learnt Implementing an integrated transition clinic, coupled with improving young adults' healthcare experience through a young adult clinic, improved patient adherence to regular medication and engagement with healthcare providers, as judged by reduced transplant failure rates. This model may be applicable to other young adult populations with chronic disease transferring to adult healthcare.

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- Reducing *Clostridium difficile* infection in acute care by using an improvement collaborative (*BMJ* 2010;341:c3359)

Background and description of context

End stage renal disease is rare in paediatric practice, with a prevalence of 9–50 per million population.[1] Kidney transplantation is the treatment of choice compared with dialysis, as it restores growth and pubertal development and reverses symptoms of renal failure. Consequently, more than 80% of young adults with end stage renal disease transferring to adult care have a functioning kidney transplant.

Adolescence is a time of increasing independence, experimentation, and rebellious behaviour influenced heavily by peer behaviour. However, experimentation may lead to risk taking behaviour, which can result in non-adherence to regular medication and reduced engagement with healthcare providers.[2 3] Registry data from the United States show reduced five year survival rates of kidney transplants in young adults (70%) compared with those in children aged <11 years (85%).[4] Transfer from well resourced, small, paediatric care programmes to resource limited, large, adult kidney care programmes can be associated with significant non-adherence with immunosuppressive drug regimens that can lead to premature transplant failure. One UK study showed that 35% of young renal transplant recipients had lost their transplants by 36 months after transfer to adult renal care.[5]

Historically there has been a disconnect between paediatric and adult renal and transplantation services, often associated with inadequate communication of important medical and social information.[6] This lack of cohesion can lead to confusion over the management of rare paediatric diseases in the adult service and a lack of trust between the young adult patient and immediate family and the new adult healthcare team. Current services for young adults moving from childhood to adult services are inadequate, with insufficient training in managing adolescent health outside mental health in the UK. This may result in the underuse of healthcare services seen in men aged 20–29[7] and the poorer levels of satisfaction of delivered healthcare in NHS surveys of 16–24 year old patients.[8]

This problem has been recognised by national healthcare bodies in the UK,[9] Canada,[10] US,[11] and internationally,[12] with the development of guidelines on transition and young adult care for patients with end stage renal disease. Guidelines in the UK have been developed jointly by the Royal College of Physicians and Royal College of Paediatrics and Child Health from consensus meetings of clinicians from various specialties and patient representatives. These recommend increased integration of paediatric and adult renal healthcare and the establishment of specific regional young adult renal services.[13] Most of the literature is descriptive with little evidence of the impact of such service reform.[14] Limited evidence of improved outcomes comes from the management of young adults with type 1 diabetes through dedicated transition clinical staff, targeted patient education programmes, and adjustments in service delivery including dedicated young adult clinics.[15]

Outline of the problem

Within three months of starting his first consultant post in the 1990s one of the authors (PH) took over the long term care of a 16 year old with a stable functioning kidney transplant. Although the young man was a model patient studying for university entry, within 12 months he had developed two late acute rejection episodes due to non-adherence to his immunosuppressive drug regimen, resulting in the loss of his transplant within two years of transfer.[16] This experience led to the establishment of an integrated paediatric-adult nephrology transition clinic at Birmingham Children's Hospital in 1999. When PH

Outcomes for young adult kidney transplant recipients before and after introduction of integrated transition from paediatric nephrology care to adult care and a young adult clinic service

	Model of transfer from paediatric to adult care	
	Direct transfer	Integrated transition and young adult service
Time period	2000–05	2006–11
Transfer process and adult care team	Single referral letter, 6 adult nephrologists	Young adult team (1 nephrologist, 1 nurse specialist, and 1 youth worker)
No of patients (male, female)	9 (3 male: 6 female)	12 (7 male: 5 female)
Median (range) age at transfer to adult care (years)	18 (16–18)	17.5 (16–18)
No (%) of late acute rejections	3 (33)	0
No (%) of renal allograft loss	6 (67)	0
Median (range) time to renal allograft loss	40 (1–62)	—
No of deaths	1 (due to miliary tuberculosis)	0

moved to Oxford in 2002 he found no transition service. Adolescents moving from paediatric care were randomly allocated to any one of six adult nephrologists in clinics at different sites. Young adults and their families suddenly found themselves isolated in a large adult clinic full of much older patients.

We set out to reduce non-adherence with immunosuppressive medication and improve engagement with clinical services by young adults with renal failure moving to adult renal services by establishing a joint paediatric-adult nephrology clinic coupled with a new young adult nephrology service in Oxford in 2006. We aimed to reduce the rate of late rejection of kidney transplants and improve renal allograft survival. The key objective was to ensure young adult patients continued to lead normal lives made possible by maintained renal allograft function.

Key measures for improvement

We compared the clinical outcomes of patients transferring through this new integrated service (years 2006–11) with those of a historical set of patients transferred directly to the Oxford adult renal service in 2000–05. Non-adherence with immunosuppression is often covert and difficult to detect and measure reliably. Late acute rejection (>6 months after transplantation) is a marker of non-adherence with immunosuppressive medication, is difficult to treat, and usually results in a significant reduction in transplant survival time and occasionally immediate transplant failure.[17]

Information gathering, analysis, and interpretation

In 2000–05 nine patients (three male, six female) with functioning kidney transplants were transferred from London paediatric centres to the care of six different adult consultant nephrologists in Oxford by single referral letter (group 1). They were then seen in standard adult nephrology clinics of mixed ages with average consultation times of 20 minutes within a four hour clinic schedule of 20 patients. Median age (range) at transfer was 18 (16–18) years.

In 2006–11, 12 paediatric transplant recipients (seven male, five female) aged 17.5 (16–18) years went through integrated transition from the paediatric nephrology units at Great Ormond Street Hospital and Evelina Children's Hospital in London to the adult nephrology centre at Oxford (group 2). They were managed by a young adult clinical team comprising a single nephrologist, transplant nurse specialist, youth worker, and pharmacist.

The demographic details of the two groups are shown in the table. Hospital electronic and patient records were accessed to record end points of transplant function at transfer and latest follow-up. Episodes of acute transplant rejection, transplant failure, and death were documented.

Strategy for change

Joint transition clinic

The pathway was designed through a period of joint consultation (fig 1) and modelled on the joint transition clinic between Birmingham and the University of North Staffordshire Hospital in 1999. The pathway involves joint medical clinics at the paediatric centres including a paediatric nephrologist and paediatric renal transplant nurse specialist jointly working with an adult nephrologist and adult renal transplant nurse specialist from Oxford. Since 2009 the team has also included a youth worker from the adult team. These joint transition clinics occur every four

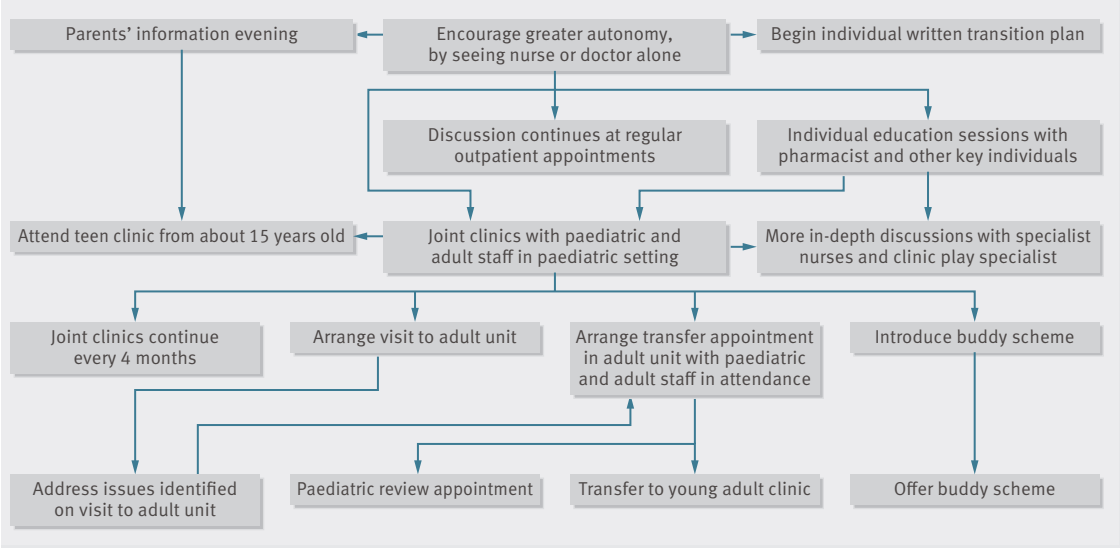

Fig 1 | Integrated pathway for transition of paediatric patients with end stage kidney disease to care in an adult renal unit

Fig 2 | Oxford Young Adult Clinic at Corpus Christi College in April 2010: clinical consultation with a transplant physician (top), pool competition in the games room (bottom). (Reproduced with patients' permission)

months and see a cohort of paediatric patients who live in the transplantation region of the adult centre (general population about three million). Patients are seen jointly by the two teams from the age of 15–18 years, and transfer to the adult clinic occurs by the age of 18 years by mutual consent of the patient, family, and the paediatric and adult clinical teams.

At each of the three hour joint medical clinics held at the paediatric centre, typically four or five patients are seen, with individual multidisciplinary consultations lasting 30–45 minutes. The patients are seen alone by the healthcare teams to promote autonomy and in preparation for the young adult clinic, when patients are usually seen individually and encouraged to take full responsibility for their healthcare. Subsequently, they are seen with family members to discuss progress and future management (fig 1). Before transfer to the adult clinic the youth worker will arrange at least one community visit, and the transferring patient will visit and look around the adult unit informally.

The resultant integrated transition pathway allows the young adult patient and his or her family to progressively gain trust in the adult healthcare team before final transfer. In addition the adult team have an opportunity to obtain a thorough de-brief from the paediatric team and gain a valuable update on rare paediatric nephrological conditions, leading to more effective and comprehensive individual adult care plans.

Young adult clinic

An additional development was the establishment of a dedicated young adult clinic in the adult unit, bringing together patients with a median age of 22 (range 16–28) with advanced chronic kidney disease or receiving renal replacement therapy. Patients attending the young adult clinic include those transferring from paediatric care (50%) and young adults directly presenting to adult services (50%). The young adult clinic was initially held in the adult hospital outpatient department, though at a different time from standard clinics. It had only partial success because of limited peer interaction, which was substantially hampered by the hospital environment.

In December 2008 the clinic was moved out of the hospital into a student college and sports centre in central Oxford, where it is held every six weeks. The objective was to develop a normal young adult environment mirroring a youth club to catalyse peer interaction between all the patients. An essential addition was the appointment of a youth worker, made possible financially by the Supporting Young Adults project from NHS Kidney Care. The youth worker (DL) acts as a bridge between the healthcare team and the patients. He coordinates the clinic day, which includes an "ice breaker" session in a nearby coffee house, lunch in the college, and use of the students' common room and games room or sports centre during the afternoon while clinical consultations take place (fig 2). His role ranges from facilitating the introduction of new young adult patients to running team events such as pool or squash competitions to catalyse peer interaction and rebuild self esteem and organising social events such as 10 pin bowling or go-karting to foster peer support. He works on a one to one basis in the community with individual patients who require extra support, which may include help with preparations for job applications and interviews and identification of issues requiring help from other members of the medical or social care team.

Transfer to a standard adult clinic

Timing of transfer to a standard adult clinic varies between individual patients and relates to educational, employment, and social development. In most circumstances the exact age of transfer is determined by the patients, who become more independent and require less support as they get full time jobs or start a family. However, some individuals remain in the clinic until their late 20s.

This strategy required restructuring of existing clinical services in Oxford and a change for the other clinicians previously managing these patients who had to relinquish clinical care to the young adult care team. Many initially had doubts about the added benefit of the young adult service. Internal progress updates and direct feedback

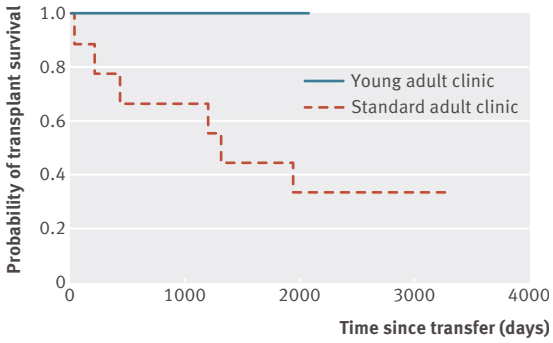

Fig 3 | Renal allograft survival (days) before and after introduction of an integrated paediatric to adult transition and young adult clinical service for patients with end stage kidney disease (log rank test, P=0.015).

from young adult patients at multidisciplinary unit meetings have changed attitudes and referral practice, such that 90% of eligible patients are now managed by the young adult service (62 patients were offered the new care pathway). A small proportion of eligible patients remain in standard adult clinics through patient or clinician choice, although all the patients transferred from paediatric to adult care now follow the integrated young adult care pathway. Young adult patients attending the clinic have regularly participated in helping to design and reshape the young adult service through surveys.

Establishing the medical, nursing, and pharmacy resource for the clinic was cost neutral since this service was previously provided in multiple existing adult clinics. Job plans have been adjusted to redistribute existing clinical activity. The youth worker post was initially created as a voluntary post in 2009 and extended to a part time post in August 2010. In addition, Corpus Christi College and Esporta North Oxford have donated their premises and facilities. Peer support social events have been supported by local fund raising both within the Young Adult Patient Group and from the Six Counties Kidney Patient Association. Even within the current financial limitations of the NHS an outreach community clinic can be established with the support of the local business and charitable community.

Effects of change

In the historical control group (group 1), six of nine patients developed transplant failure at a median of 40 (1–62) months after transfer to adult care. In group 2 there have been no transplant failures at a median follow-up of 26 (18–60) months after transfer (fig 3). Late acute rejection occurred in 33% of group 1 and none in group 2. Transplant survival in group 2 compared favourably with that in a historical cohort of teenage kidney transplant recipients transferred to standard UK adult services.[5]

Next steps and discussion

The introduction of an integrated transition service for teenage kidney transplant recipients has led to a reduction in the rate of transplant loss and reduced morbidity and admissions. Since we have only before and after data, it is possible that other aspects of clinical management may have influenced the outcome. However, during this time there has been no important change in the standard immunosuppression protocols used by the two paediatric nephrology units. Furthermore, the rate of renal allograft loss is substantially lower than the 35% loss found in another cohort of young adult kidney transplant recipients in the Trent region of the UK, where no dedicated transition or young adult service was in place.[5]

The impact of the combined approach of an integrated paediatric-adult transition clinic coupled with transfer into a young adult clinic at the adult service is consistent with improved short term outcomes (improved haemoglobin A_{1c} levels) observed with dedicated transition clinics for patients with diabetes.[15] Non-adherence with clinic appointments is an additional outcome marker, and improved attendance rates have been observed in a diabetic population within joint paediatric-adult transition clinics.[18]

The Oxford-London model is consistent with the need to start transition early[19] and the beneficial effect on clinical trust when a young adult patient meets the adult clinicians before transfer, as shown in an adult heart transplant service.[20] The recognition that development of the adolescent brain extends to beyond the age of 20 years supports the concept of emerging adulthood and the potential benefit of the young adult clinic model.[21 22] A key theme supported by this model is the gradual transfer of responsibility for care from the parent or carer to the individual young adult.[23 24] The integrated approach enables progressive transfer of clinical responsibility of care to the adult healthcare team while the paediatric team and adult youth worker can work on increasing autonomy of care from the parent or carer. Youth workers predominantly work with young people aged between 11 and 25 years in the community, and most hospital healthcare teams will not be familiar with them. Key components of youth work are facilitating personal and social development, providing personal support, building and enhancing self esteem, and promoting young people's views.[25] Support from the youth worker and interaction with peers in a similar medical situation can help individual teenage patients overcome the issues faced by managing a chronic illness while going through the challenges of adolescence. In a model without integration at transfer fewer than 20% of young adults with chronic kidney disease were perceived to function autonomously.[26] It is important to consider other outcome measures, including educational achievement, vocational attainment, and psychosocial outcomes, which are known to be reduced in young adults with chronic disease.[27] We are currently conducting a questionnaire and structured qualitative interview study of the people attending our young adult clinic population to determine the impact of end stage renal disease on these measures.

It is important to design clinical pathways for young adults that suit their lifestyles. The use of text messaging in young adults with liver transplants has, for example, led to improved compliance with immunosuppression regimens and reduced rejection rates.[28] The creation of a youth environment by hosting the follow-up clinics in a college, sports centre, and coffee shop is core to the customisation of the clinic to our teenage patients. We also regularly use

text messaging, emails, and social network sites to facilitate interaction between the patients, youth worker, and healthcare team.

Delivery of a comprehensive young adult service requires the participation of multidisciplinary healthcare and social care professionals. We show that this can be delivered in an effective way with minimal implementation costs, in line with similar observations by Bent, who found young adult team care for patients with physical disabilities was no more expensive than ad hoc services for adolescents and young adults.[29] Our integrated service potentially reduced healthcare costs by reducing the number of failing kidney transplants and offsetting the need for expensive maintenance dialysis and its associated morbidity.

Integrated paediatric-adult transition services in nephrology still seem to be the exception. At a recent workshop of trainee paediatric nephrologists at the European Society of Paediatric Nephrology, only one of 35 major paediatric nephrology centres across Europe had an integrated transition clinic with adult care (personal communication, PH). In the UK, however, similar integrated transition and young adult clinics have recently been established in several other regions of England, including Birmingham, Bristol, London, Nottingham, Leeds, Newcastle, and Sheffield. NHS Kidney Care is currently providing financial support to explore improved care models for this age group across England, and we have stimulated international collaborations with the University of Colorado and Yale medical centres to explore development of a similar service in a different healthcare system.

A similar strategy may also be applicable to young adults with other major chronic illnesses, including diabetes, chronic joint and connective tissue disorders, cystic fibrosis, inflammatory bowel disease, and haematological disorders. All such young adult patients experience geographical and peer group isolation, and our integrated approach is equally applicable to patients with relatively common diseases such as diabetes or rarer ones such as kidney disease and inflammatory bowel disease.

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Contributors: PNH developed the new care model and designed this clinical practice study. He collected the data and performed the analysis and wrote the main draft of the manuscript. He will act as guarantor. The other authors were all involved with the design and implementation of the new care pathway. They reviewed the results and contributed to editing and writing the manuscript.

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Competing interest: PNH is currently a clinical adviser to NHS Kidney Care on transition and young adult renal care in the UK. Otherwise there are no potential conflicts of interest. All other authors have completed the Unified Competing Interest forms and declare no support from any organisation for the submitted work; no financial relationships with any organisation that might have an interest in the submitted work in the previous three years and no other relationships or activities that could appear to have influenced the submitted work.

This clinical practice study did not require ethical approval.

Patient consent obtained.

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