

education

FROM THE JOURNALS Edited highlights of weekly research reviews

Switching hour

Every GP has a handful of patients who ask that their medication comes from the same manufacturer each time it is dispensed. GPs' responses can vary from "No, they're all exactly the same" to agreeing to any switch to a branded version of the drug—for which you have to fend off any number of on-screen prompts and pop-ups urging you not to. I think most of us are somewhere in the middle, and sometimes add a request to the pharmacist on the prescription if it's a generic drug available from several manufacturers.

A study in *JAMA Internal Medicine* offers some helpful reassurance when it comes to generic levothyroxine: from a database of over 15 000 adults in the US who filled a prescription for generic levothyroxine between 2008 and 2019, 17.6% switched between different generic versions of the drug. They found that 84.5% of "switchers" and 82.7% of non-switchers had a normal thyroid stimulating hormone level, and similar mean hormone levels in the two groups as well.

• *JAMA Intern Med* doi:10.1001/jamainternmed.2022.0045

Hernia recurrence rates

The NHS website page on hernia repair says only that a small number of hernias come back after surgery. I'm not sure what a "small number" is: maybe 1, or 5%, or 16.1%? Reviewing the records of 175 000 patients who had undergone a hernia repair between 2007 and 2018 in the US, researchers calculated a 10 year risk of having further surgery for recurrence of the hernia of 16.1%—around 1 in 6, down a bit from 1 in 5 when it was last studied 20 years earlier. But having an operation for recurrence isn't the same as recurrence and will miss those who have either decided or been told that it's not worth trying again, so the real risk of recurrence may be higher. Then again, patient and healthcare system characteristics might mean that recurrence rates are very different between those using Medicare in the US—as in this study—and people in the UK using the NHS.

• *JAMA* doi:10.1001/jama.2022.0744

Troponin thresholds after cardiac surgery

How do you diagnose a myocardial infarction (MI) after cardiac surgery? The usual clues of an MI—chest pain, ECG changes, and abnormal cardiac biomarkers/enzymes—are all much harder to decipher in the days after operating on the heart. High sensitivity troponin tests are still used but lack specificity in this context. A large multicentre prospective cohort study explored the relationship between peak high sensitivity troponin I measurement in the three days after cardiac surgery and 30 day mortality. The hazard ratio for death at 30 days

went above 1 only when peak troponin levels went above 218 times the usual upper reference limit for the test—suggesting that current thresholds for troponin monitoring after cardiac surgery may be too low. These findings need validating before they can be applied to practice, and the study assessed only one type of assay. The mechanism for excess mortality in those with the 218-fold or more troponin elevations also needs further exploration.

• *N Engl J Med* doi:10.1056/NEJMoa2000803

RSV prevention

With all the debate we've seen over covid vaccination in children, I wonder what the uptake would be of a drug aimed at preventing lower respiratory tract infection associated with respiratory syncytial virus (RSV). Annual RSV waves lead to a lot of children being admitted to hospital—around 30 000 under 5s per year in the UK—and around 30 deaths. Nirsevimab is a monoclonal antibody that blocks RSV from entering host cells. A double blind randomised control trial recruited healthy late term (>35 weeks) and term babies to receive an intramuscular injection of nirsevimab or placebo. The primary endpoint was a "medically attended lower respiratory tract infection" due to RSV within 150 days: and, of the 1490 babies randomised, this occurred in 1.2% of those in the nirsevimab group versus 5% in the placebo group—an efficacy of 74.5% ($P<0.001$). However, there was no statistically significant reduction in hospitalisations due to the virus in those given nirsevimab.

• *N Engl J Med* doi:10.1056/NEJMoa2110275

Spray dangers

The *New England Journal of Medicine* reports four cases of melioidosis linked to a widely available aromatherapy spray sold by the supermarket Walmart. A 5 year old and 53 year old died from the infection, a 4 year old was left wheelchair-bound and non-verbal, and another 53 year old was discharged to a transitional care facility with persistent confusion and osteonecrosis of the hip. Whole genome sequencing allowed the strain of the bacterium *Burkholderia pseudomallei* to be matched to that found in the aromatherapy room spray, which was imported from India where the Gram negative bacterium is endemic. Clinical features varied but included fever, respiratory failure, and confusion. Two of the cases were detected with blood cultures, one from a joint aspirate, and one at postmortem examination.

• *N Engl J Med* doi:10.1056/NEJMoa21116130

Tom Nolan is a clinical editor; sessional GP, Surrey, *The BMJ*, London

Cite this as: *BMJ* 2022;376:o598

Assessing tics in children

Valsamma Eapen,^{1 2 3} Tim Usherwood^{4 5}



0.5 HOURS



See <http://learning.bmj.com> for linked learning module

¹University of New South Wales, Sydney

²South Western Sydney Local Health District

³Ingham Institute of Applied Medical Research, Liverpool, Australia

⁴Faculty of Medicine and Health, The University of Sydney

⁵The George Institute for Global Health, Sydney

Correspondence to: V Eapen v.eapen@unsw.edu.au

Motor and/or vocal tics are relatively common, occurring in about 1% of children of school age. They are also a characteristic of Tourette's syndrome, a neurodevelopmental disorder in which multiple motor tics and one or more vocal tics have been present for more than a year. Tic disorders are often undiagnosed or misdiagnosed.¹ This article outlines a general approach for primary care clinicians to assess a child who has a tic. We highlight the different considerations depending on the age of the child and the presenting symptoms.

Tics vary in type, frequency, and severity over time. They are usually preceded by a premonitory sensation in the form of a stretch/tension or tingling at the site of the tic or a mental urge which is relieved by performing the tic.² Typically, the relief lasts for a short period and the urge returns. Tics can be voluntarily suppressed for seconds to minutes or several hours (eg, some children may suppress them at school) and this may be followed by a rebound. Frequency of tics is usually reduced when the child is relaxed, focused, or when distracted, such as while playing sports or a musical instrument. Tics are typically made worse by stress, anxiety, lack of sleep, or tiredness.

HOW PATIENTS WERE INVOLVED IN THE CREATION OF THIS ARTICLE

TU has lived with Tourette's syndrome for more than 60 years. The manuscript was discussed with executives from the Tourette Syndrome Association Australia and in particular Robyn Latimer (RL), who reviewed the manuscript and whose views helped shape the section on management strategies to assist young people with tics.

WHAT YOU NEED TO KNOW

- Up to 20% of children develop a motor tic as part of their development; most tics last from a few weeks to months
- Tourette's syndrome is characterised by multiple motor and one or more vocal tics lasting for more than one year
- Tourette's syndrome is often associated with comorbidities including obsessive compulsive disorders, obsessive compulsive behaviours, attention deficit/hyperactivity disorder, or autism

LIVING WITH TOURETTE'S SYNDROME

My first memory of a tic was repeated grunting in my primary school classroom, much to the irritation of my teacher and amusement of classmates. Some weeks later, I saw my father wrinkle up his nose in response to an unpleasant smell. My grunting gave way to nose wrinkling.

Over subsequent months and years, I acquired new tics and lost earlier ones. They became more complex, often combining grunting with other movements, and mainly affecting my face, neck, shoulders, and arms. Inevitably, my nickname at school was "Twitch." Although I saw several doctors and a child psychologist, my condition remained undiagnosed until I was at university. In my third year of medicine, I asked our psychiatry lecturer if he could explain the cause of my tics. He referred me to a neurologist, and it was an enormous relief when I received a diagnosis of Tourette's syndrome. At last I had a reason, and a way of talking about my symptoms.

Fatigue and mental concentration can exacerbate the frequency of tics. Music and physical activity reduce the urge

After a brief and unsuccessful trial of medication, I learned to live with Tourette's syndrome. At times the tics are socially embarrassing, but they have also been the source of shared amusement. I have never experienced coprolalia but I am aware of a temptation to copy the verbal and non-verbal tics of others. Occasionally, I have left the room to avoid "catching" a tic. I am now 68. My tendency to tic has reduced markedly over the last decade or so, but is still present when I feel stressed. Fatigue, study, and mental concentration can exacerbate their frequency. Listening to music and taking part in physical activity both reduce the urge. The tics are part of who I am—not particularly welcome—but as much a part of my makeup as my eye colour.

Tim Usherwood

Assessment

Parents may seek medical advice if the tics are bothersome, cause unwanted attention or embarrassment because of the frequency, type, site, and nature of tics, or because they are causing pain (eg, because of repeated movements). Parents may also seek advice about the significance or causes of the tics. An initial assessment might aim to:

- *Distinguish tics from other involuntary movements*—(eg, chorea, athetosis, dystonia) or stereotypies. Stereotypies are repetitive purposeless movements such as hand flapping. They can be primary with no underlying condition (often self-limiting or adaptations are made to camouflage the movement) or secondary (eg, restricted repetitive behaviours or self-stimulatory behaviours such as rocking, which are more prevalent in children with autism or a learning disability) (table; box 'Additional resources')
- *Assess for comorbidities*³—including obsessive compulsive disorder (OCD), obsessive compulsive behaviour (OCB), attention deficit/hyperactivity disorder (ADHD), depression, anxiety, learning disability
- *Assess for psychosocial issues*—consider school functioning, family and friendships, self-esteem, and the impact on quality of life.¹

How to differentiate tics from stereotypies		
Characteristic	Tic	Stereotypy
Type of movement	Brief, quick, rapid, or abrupt	Rhythmic, coordinated, and purposeful
Site	Mainly head and neck region	Mostly limbs or the entire body
Associated urge	Preceded by a premonitory urge which is relieved by the tic	No associated urge and no relief
Suppression	Can voluntarily suppress for brief periods but at the expense of mounting inner tension	Not voluntarily controlled but may be reduced with distraction
Fluctuation	Waxing and waning course	Constant without much variation
Congruence	Ego-dystonic (not in line with or in agreement with one's own thoughts, values, and feelings)	Ego-syntonic (consistent with and acceptable to one's own thoughts, values, and feelings)
Onset	Typically around 6-7 years of age	Typically at <3 years of age
Course	Change in site and type, with one type of tic being replaced by another	Movements remain unchanged with a fixed pattern
	Stress and anxiety may make it worse	No specific link but may do it for self-soothing
	Usually reduce with age by late adolescence/young adulthood	No specific change with age
Examples	Blink, jerk, twitch, nod	Rocking, hand flapping, waving
Relevant history	Personal or family history of tics, OCD/OCD or ADHD	Personal or family history of learning disability, autism

Table 2 | Common tic symptoms and associated features

	Motor tics	Vocal tics
Simple	Blinking, rolling of eyes, nose or face twitch, mouth movements (such as mouth pout, mouth open, mouth to the side), facial grimace, shoulder shrug, arm jerk, tongue movements, head nod, neck stretch, abdominal contractions, leg jerk	Grunt, throat clear, cough, sniff, animal sounds, squeak, shriek, low or high pitched sounds, gasp, nosy breathing, noisy breathing, gulp, click
Complex	Tapping, forced touching, kissing self/others, lick, smell, spit, stamp, hop, jump, skip, turn, bend, kick, hit, unusual walking. Copropraxia: involuntary obscene gesturing; socially inappropriate touching, eg. genitals of self/others. Echopraxia and suggestibility: copying/repeating other people's actions/movements; needing to tic when seeing/talking about tics. Non-obscene socially inappropriate actions	Echolalia: repeating word, phrase, sentence. Coprolalia: involuntary swearing. Non-obscene socially inappropriate comments

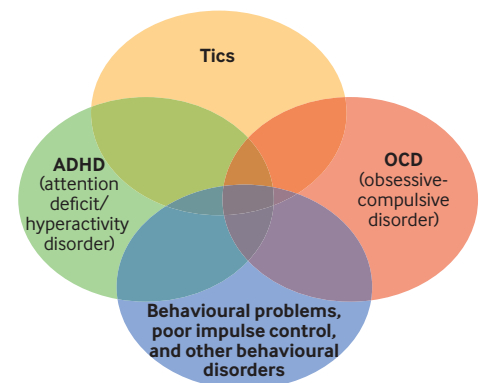


Fig 1 | Common comorbidities in Tourette's syndrome

A first presentation of a child with a tic

A 7 year old boy, Tom, is brought to the general practitioner (GP). His mother reports that recently he has had a dry cough and has been twitching his nose. She wonders if this is caused by an allergy. Last year Tom saw an ophthalmologist for excessive blinking but nothing abnormal was found.

Potential diagnoses here include a primary tic disorder (box 1),⁴ transient developmental tics, mannerisms, or stereotypies. Seek a detailed description of the tic characteristics (table 1) and presence of any previous or current tics or family history. Ask about the type, nature, frequency, intensity, and impact of tics, noting that they can be motor or vocal and may be simple or complex (table 2). Involuntary swearing (coprolalia) is present in 20-30% of people with confirmed Tourette's syndrome. Depending on the first symptom, families may be concerned about a range of possible causes, including stress,

Box 1 | Types of primary tic disorders

- Transient or provisional tic disorder: tics persisting for less than 12 months
- Chronic or persistent tic disorder: multiple motor tics or vocal tics lasting >1 year
- Tourette's syndrome: multiple motor and one or more vocal tics lasting >1 year

allergies, conditions of the eye, nose, or throat, and more recently covid-19.

Up to 20% of children have motor tics as part of their development, but these usually last for only a few weeks to months.⁵ In Tom's case, his parents report excessive blinking (a possible motor tic) a year ago, and now nose twitching, another motor tic, as well as cough, a likely vocal tic, so that a diagnosis of Tourette's syndrome should be considered. Tourette's syndrome is three to four times more common in boys; tics typically start at the age of 6-7.⁶

Tourette's syndrome is a clinical diagnosis.⁷ Patients and their families find it helpful to have a clear diagnosis, along with information about the putative cause, likely prognosis, management options,⁸ and associated comorbidities.⁹ As the tics are not causing any problems for Tom, no active intervention is needed at present, and the family can be advised that it is best to ignore the tics, as drawing attention to them (including asking Tom to stop) may make symptoms worse. Direct parents and carers to websites that provide accurate and reliable information. Families may also find it helpful to know that many famous and successful people have had Tourette's syndrome.¹⁰

Box 2 | Strategies to help young people with tic disorders

- Psychoeducation of young person, family, teachers and peers
- Provide proactive (not reactive) support and predictable routines
- Provide breaks, with opportunities for physical movement
- Designate a safe place to go to when tics are severe, with a pre-agreed pass or signal for time out
- Preferential seating (eg, front of the class, close to the door)
- A buddy for learning and social support (may help prevent bullying)
- Planning/managing communication about tics (to school, peers/friends, employer) and self-advocacy (how to respond if asked about tics)
- Allow scribe/computer if writing is affected; special provisions for examinations—seating in a separate room, allowing extra time
- Identify and avoid triggers; manage stress, anxiety, or boredom
- Encourage relaxing activities and foster strengths and hobbies to boost self-esteem
- Join support groups to share experiences and attend activities or events such as camps

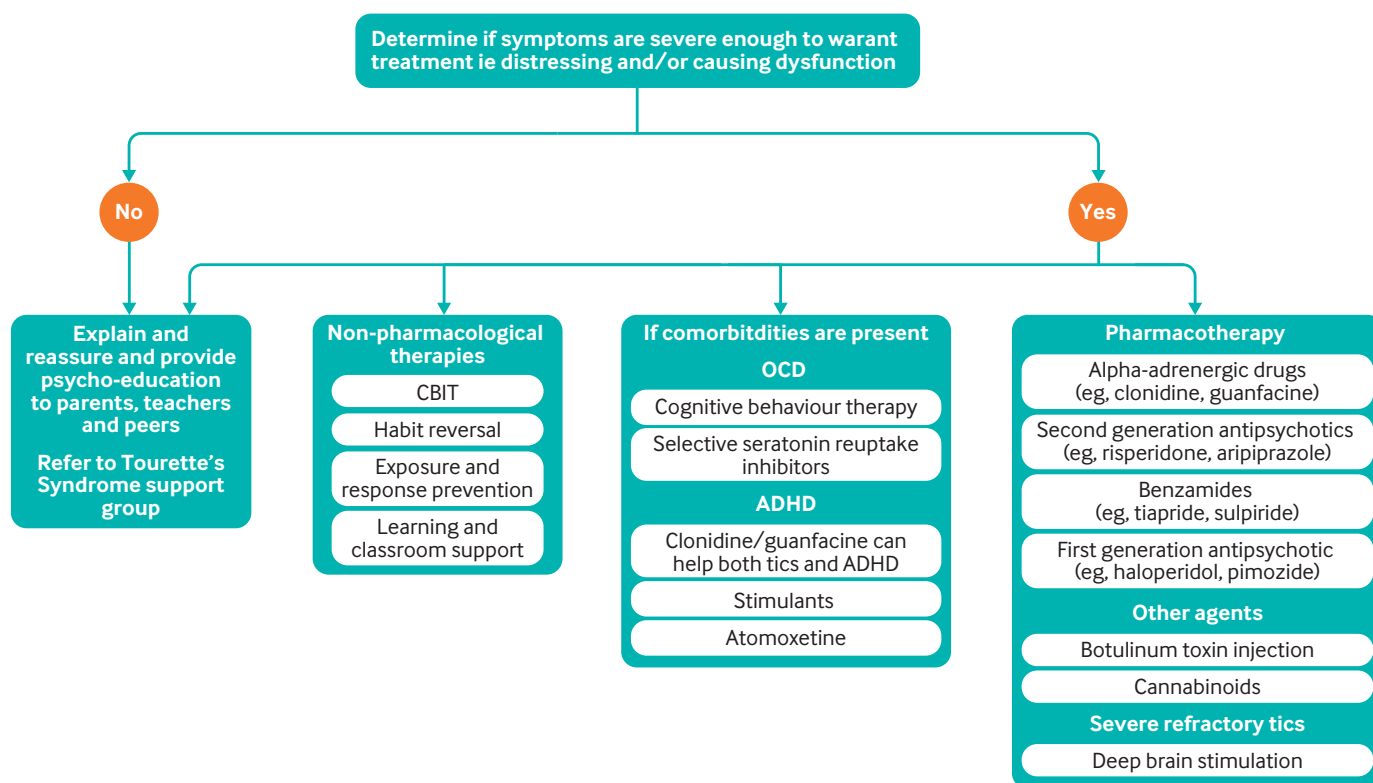


Fig 2 | Management for a patient with a tic disorder. CBIT=cognitive behavioural intervention for tics

Tics presenting with associated comorbidities

Sam presents with his mum to the GP clinic. His mum says that Sam is having significant problems at school and was recently assessed by the learning support team for poor attention and disruptive behaviours, including pulling faces at the teacher and disturbing the class by making silly noises. Sam also complains that he is not able to do some of the sums in his maths class as he has to convert everything into even numbers because he is not able to work with odd numbers.

In around 90% of people attending specialist clinics, Tourette's syndrome is associated with comorbid conditions such as ADHD and (less commonly) autism spectrum disorder (ASD).⁶ It is also associated with OCD and OCB (eg, obsession with specific numbers or symmetry, "evening up" behaviours such as action on one side and then the other to make it "even," or doing things until it feels "just right" that are commonly associated with tics but often do not reach the threshold of clinical disorder diagnosis because of not fulfilling the distress and dysfunction criteria). Ask about tics and these comorbid conditions in the patient and in family members.¹¹ Certain genes have been implicated in Tourette's syndrome and in its links to ADHD and OCD.¹²

People with Tourette's syndrome may also have anxiety, depression, problems with sleep, self-injurious behaviours, anger or rage, poor impulse control and behavioural disinhibition, disruptive disorders, and learning disorders (fig 1).⁵ When behavioural or mental health difficulties are the presenting complaints, tics may be missed. In Sam's case, at times the comorbidities are more problematic and will need more intervention than tics themselves.¹³

EDUCATION INTO PRACTICE

- What advice and resources might you offer Sam and his parents on first presentation?
- How would you screen for comorbidities in a patient with possible Tourette's syndrome?
- Who among your patients has possible or confirmed Tourette's syndrome? Based on this article, what changes to their management might you offer?

Initial management and referral

Figure 2 details the general principles for managing tics. Provide information and resources to parents and school, explaining that tics are outside the child's control. Box 2 offers some helpful strategies to minimise the negative effects of tics on a young person's life. Simple tics causing no distress or dysfunction might benefit from watchful waiting, but if pain (caused by repeated movements), distress, or dysfunction occurs, empirically supported drug¹⁴ and behavioural interventions¹⁵ are available.¹⁶ Consider referring to a specialist (eg, paediatrician, child psychiatrist) if the patient has symptoms, whether from comorbidities or from tics, that remain problematic despite initial management. Refer to a neurologist for sudden-onset chorea, ataxia, or dystonia; to a mental health specialist for comorbidities including anxiety, mood, or obsessive compulsive disorder; or to a neurodevelopmental specialist for ADHD or autism.

Prognosis

Tics typically reduce by late adolescence or early adulthood, with remission in 30-50%. Around 20% have moderate to severe tics,¹⁷ and 5% experience debilitating or refractory tics in adulthood.¹⁸

Competing interests: None declared.

Cite this as: *BMJ* 2022;376:e069346

Find the full version with references at doi: 10.1136/bmj-2021-069346

PRACTICE POINTER

Discussing prognosis and what matters most for people with serious illness

Justin J Sanders,^{1 2} Leigh Manson,³ Deborah Constien,⁴ James Downar^{5 6}

¹Palliative Care McGill, Department of Family Medicine, McGill University, Montreal

²Ariadne Labs, Brigham and Women's Hospital and Harvard TH Chan School of Public Health, Boston, Massachusetts

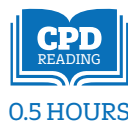
³Health Quality and Safety Commission, New Zealand

⁴Madison, Wisconsin

⁵Department of Medicine, University of Ottawa

⁶Bruyere Continuing Care, Ottawa

Correspondence to: JJ Sanders justin.sanders@mcgill.ca



0.5 HOURS



Technological advances in medical care give clinicians unprecedented capability to prolong life. However, this may not be appropriate for patients with serious illness. Serious illness refers to health conditions that carry a high risk of mortality, poor function and quality of life, and strain on caregivers.¹ For people with serious illness, life prolonging treatments may not align with their preferences or help meet their goals, and may increase their suffering and that of their family members. A multi-site observational study on patients with serious illness and a randomised controlled trial on patients with advanced cancer suggest that people with serious illness commonly express goals beside simply living longer. Those who recognise that they are nearing the end of life generally prefer care focused on quality of life and increased time spent at home.^{2 3}

One US cohort study looked at discussions about end-of-life (EOL) care in more than 2000 patients with advanced

cancer. The study^{4 5} found that clinicians often failed to engage even their sickest patients in conversations about their goals and preferences until it was too late, if they did so at all.⁴ In a randomised controlled trial with embedded qualitative methods, conversations with 25 seriously ill patients were analysed. These conversations typically focused on cardiopulmonary resuscitation or transition to a hospice.⁵ The conversations also failed to include discussion of prognosis, even when desired—and the goals and preferences that might inform such treatment decisions.⁵ This leaves patients and caregivers at risk of unwanted and invasive treatments, as well as psychological distress. It may undermine the possibility for growth and transcendence at the end of life.⁶ It may also explain why caregivers of those who died of advanced cancer report higher EOL quality of care with longer hospice stays, and lower quality of care when loved ones received care in an intensive care unit or died in hospital.⁷

Data from a 1996 nationally representative survey of 3747 nursing home residents in the US suggest that failure to engage patients in conversations about treatment preferences in serious illness affects ethnic minorities more acutely.⁸ For example, despite a desire to engage in such conversations, black Americans are less likely to have such conversations,⁹ more likely to receive invasive treatment at the end of life, including cardiopulmonary resuscitation and mechanical ventilation,¹⁰ and are less likely to use hospices.¹¹ Similar trends are seen with other ethnic minority groups and non-majority cultural groups in Canada¹² and Australia.¹³ These conversation gaps and the related outcomes have been exposed and exacerbated by the covid-19 pandemic and continue to present an urgent opportunity for quality improvement.

WHAT YOU NEED TO KNOW

- Serious illness is a health condition that carries a high risk of mortality and either negatively affects a person's daily functioning or quality of life or excessively strains his or her caregivers. Examples include advanced cancer, end stage organ disease, or motor neuron disease
- High quality communication that improves awareness of prognosis and elicits patients' goals and preferences can improve care quality and patient experience
- Clinicians can use structured, evidence based tools, like the Serious Illness Conversation Guide, to engage patients in such communication
- Health systems can support the delivery of high quality serious illness communication through strategies to identify patients with serious illness, train clinicians, prepare patients and families, and ensure documentation is accessible across multiple points of care



INTERNATIONAL CHOOSING WISELY STATEMENTS

- Don't offer tests or treatments without establishing your patient's prognosis, preferences, and goals of care. Potentially harmful or overly aggressive tests or treatments may be avoided by having discussions about goals and wishes, and documenting this information (Choosing Wisely Canada).
- Don't recommend aggressive or hospital level care for a frail older person without a clear understanding of the individual's goals of care and the possible benefits and burdens (US Choosing Wisely Society for Post-Acute and Long-Term Care Medicine)
- For patients with limited life expectancy (such as advanced cardiac, renal, or respiratory failure, metastatic malignancy, third line chemotherapy) ensure that a "goals of care" discussion occurs at or prior to admission to intensive care (ICU). For patients in ICU who are at high risk for death or severely impaired functional recovery, ensure that alternative care focused predominantly on comfort and dignity is offered to patients and their families. (Choosing Wisely Australia <https://www.choosingwisely.org.au/recommendations/anzics1>)
- Do not delay or avoid palliative care for a patient with metastatic cancer because they are pursuing disease directed treatment (Choosing Wisely India)¹⁴

Evidence for change

A growing body of evidence and a number of recommendations from Choosing Wisely campaigns in several countries support the integration of serious illness conversations as a standard component of care for those with serious illness (box). Such conversations aim to enhance prognostic awareness and elicit patients' goals and preferences before making recommendations and decisions about treatment. Evidence from a longitudinal cohort study on patients with advanced cancer in the US showed an association between these types of conversations and less invasive EOL care, greater use of hospices, improved quality of life, and less distress for caregivers.¹⁵

A recent randomised trial focused on an intervention called the Serious Illness Care Program.¹⁶ In this trial of 91 oncology clinicians and 278 advanced cancer patients in the US, clinicians were trained in the use of a structured Serious Illness Conversation Guide (fig 1). The study found a 50% reduction in moderate to severe anxiety (10.2% versus 5.0%) and depression (20.8% versus 10.6%) in the patient group.¹⁶ Developed with iterative input from and testing with patients and clinicians from a variety of disciplines, the Serious Illness Conversation Guide includes a series of statements and open ended questions designed to open conversations in ways that are psychologically safe, assess information preferences to support tailored prognosis communication, explore goals and values, and support person centred care recommendations.

In a pragmatic trial among 124 high risk primary care patients, those who had serious illness conversations with clinicians trained in the use of the guide had reduced healthcare costs in the last six months of life (\$8876 versus

Conversations aim to enhance prognostic awareness and elicit patients' goals and preferences before making recommendations

\$6297), likely as a result of decreased hospitalisation.¹⁷ A 2019 systematic review evaluated studies that used structured tools to support advance care planning, some of which included patients with serious illness.¹⁸ The review found that conversation guides supported different phases of advance care planning.¹⁸ Mixed and inconsistent outcomes from predominantly observational studies and lack of transparency around interventions did not enable comparison across interventions.

In addition to highlighting improved clinical outcomes, evidence supports certain characteristics from which conversations about prognosis and preferences benefit. One qualitative study of patients hospitalised at tertiary medical centres in Canada described helpful physician behaviours in these conversations.¹⁹ These included attempts to understand and acknowledge the impact of patients' histories and family roles on their preferences, as well as "conditional candour," which characterises the assessment of patient readiness for and sensitive delivery of information.¹⁹ These principles are also embedded into the Serious Illness Conversation Guide.

PATIENT PERSPECTIVES

Doctors are good at asking questions that help make a diagnosis, but not as good at asking questions that help understand the person receiving the diagnosis. The Serious Illness Conversation Guide is a clinical tool that can place patients' goals and desires at the centre of their care. This conversation guide can empower caregivers and the medical team by informing them of the patient's specific goals and care preferences. This tool may help ensure that a patient with serious illness lives and receives treatment that aligns with their values and can, for example, surface and realise a desire to receive palliative care at home rather than intensive care in a hospital.

Serious Illness Conversation Guide



PATIENT-TESTED LANGUAGE

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want and avoid treatments that cause more harm than good – **is this okay?**"

ASSESS

"What is **your understanding** now of where you are with your illness?"

"How much **information** about what is likely to be ahead with your illness would you like from me?"

SHARE

"I want to share with you **my understanding** of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time, but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."

OR

Time: "I **wish** we were not in this situation, but I am **worried** that time may be as short as _____ (express as a range, e.g. days to weeks, weeks to months, months to a year)." OR

Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."

EXPLORE

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"
(e.g. Struggling to breathe, being alone, depending entirely on others)

"What **abilities** are so critical to your life that you can't imagine living without them?"

"What **helps you** through the tough times?"

"If you become sicker, **how much are you willing to go through for the possibility of gaining more time?**"
(e.g. the ability to communicate, the ability to interact with others, the ability to control your bodily functions.)

"How much does your **family** know about your priorities and wishes?"

CLOSE

"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we _____. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

This conversation guide was adapted from Ariadne Labs: A Joint Center for Health Systems Innovation (www.riadnelabs.org) between Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health, in collaboration with Dana-Farber Cancer Institute. Reviewers of this resource included Choosing Wisely Canada's Serious Illness Working Group. Licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License, <http://creativecommons.org/licenses/by-nc-sa/4.0/>

These are not one-and-done conversations; however, the first of these conversations can open doors for ongoing discussion in ways that can be transformative

Disease based and functional indicators of serious illness	
Disease based indicators	Functional indicators*
Advanced cancer (stage IV or primary brain cancer)	Reduced ambulation or increased time in bed
End stage organ disease (heart, kidney, liver, lung)	Decrease in ability to participate in activities
Motor neuron disease	Requires assistance with self-care
Dementia	Reduced oral intake
Frailty	Altered level of consciousness

*Derived from Palliative Performance Scale (PPSV2)²²

Barriers to change

The American College of Physicians High-Value Care Task Force and primary care clinicians have identified several important barriers to ensuring access to high quality communication about prognosis, goals, and preferences for those with serious illness. Clinician barriers include insufficient communication skills training and time, competing responsibilities, uncertainty about who is at high risk of dying (and therefore seriously ill), who should initiate conversations, and prognostic uncertainty.^{20 21} The table lists disease and functional indicators of serious illness. There has been increased recognition of the role that policies and institutions play in reinforcing and dismantling these barriers to care quality.²³ A qualitative study, conducted in the US, explored the implementation of the Serious Illness Care Programme in six primary care clinics.²⁴ Based on interviews with 14 clinicians, the findings supported the value of institutional culture in promoting conversations earlier in the course of illness. Communication on aspects of prognosis that addressed function and quality of life were also identified.²⁴

EDUCATION INTO PRACTICE

- What is my current practice in engaging patients around shared decision making?
- What strategies can I use to communicate prognosis in ways that are patient centred and do not rely on statistics?
- How can my healthcare system or clinical environment better support me and my patients to have conversations that elicit what matters most?

How should we change our practice?

For clinicians caring for those affected by serious illness (physicians or advanced practice nurses in general or specialist practice), we suggest the following practice changes.

Do not offer tests or treatments without first considering the patient's prognosis, sharing it to the degree that it is desired, and understanding what matters most to them, including their preferences and goals of care. To support high quality person centric decision making, consider using a structured, evidence based communication tool, like the Serious Illness Conversation Guide (fig 1). Use this together with the following preparatory reflective activities that may facilitate implementation of the tool:

- Understand one's own cultural values, beliefs, and practices, as well as the way they affect one's practice
- Understand the assumptions, biases, and stereotypes that inform one's own thinking about patients from one group or another
- Identify power dynamics and their role in conversations with people experiencing the vulnerability of serious illness
- Cultivate communication skills that support patients in difficult moments, such as responding to emotion.

These are not one-and-done conversations; however, the first of these conversations can open doors for ongoing discussion in ways that can be transformative and relationship building.

Health systems, ranging from single clinical sites to large multi-hospital enterprises, can support clinicians and patients by adopting systematic approaches and adapting them to local context through quality improvement approaches. These include:

- Identifying patients with serious illness, and therefore in need of a serious illness conversation
- Preparing patients in advance through the use of related tools (see workbook referenced in box "What patients need to know")
- Encouraging inclusion of loved ones, if desired
- Supporting communication training (eg, in the use of the Serious Illness Conversation Guide) for all members of the interprofessional team
- Ensuring consistent places to document such conversations, such that patients' goals and preferences are easily identified at multiple points of care.

Competing interests: None declared.

Cite this as: *BMJ* 2022;376:e067572

Find the full version with references at doi: 10.1136/bmj-2021-067572

HOW PATIENTS WERE INVOLVED IN THE CREATION OF THIS ARTICLE

A patient advocate (DC) was involved at every stage of writing, drafted the section on patient perspectives, and provided critical review of all manuscript sections.

HOW THIS ARTICLE WAS CREATED

This article was created through iterative written conversation that reflects a non-systematic review of the available evidence around serious illness conversations and the gaps in care that they intend to address, as well as the professional and personal experience of an international and geographically diverse group of stakeholders.

ENDGAMES

CASE REVIEW

A young man with red eye

A man in his 30s had left eye redness for three days. He attended a local clinic where acute conjunctivitis was diagnosed, but symptoms did not improve after applying topical fluorometholone 0.1% and sulfamethoxazole 4% four times daily for two days to treat acute conjunctivitis. He attended the ophthalmology clinic for further treatment. His best corrected visual acuity in the right eye was 20/20; visual acuity in the left eye could not be measured because of severe pain and tenderness. On slit lamp examination (figure), there was

left eye lid oedema, subepithelial infiltrates, conjunctival chemosis, and excessive mucopurulent discharge on the ocular surface. The patient also reported dysuria and a whitish urethral discharge for one week; and a new sexual contact three days before the onset of these urethral symptoms.

1 What is the most likely diagnosis?

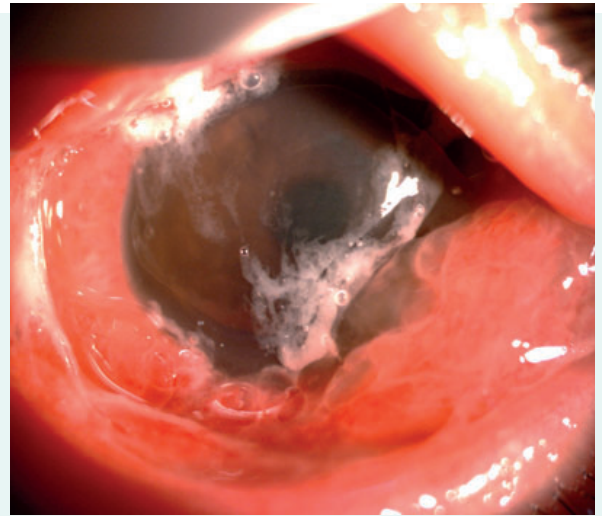
2 What are the differential diagnoses?

3 How would you treat this condition?

Submitted by Chun-Hsiang Chang and Yi-Hsun Huang

Patient consent obtained

Cite this as: *BMJ* 2022;376:e064287



Slit lamp image of the left eye, showing subepithelial infiltrates, conjunctival chemosis (swelling and oedema), and mucopurulent discharge

If you would like to write a Case Review or Spot Diagnosis for Endgames, please see our author guidelines at <http://bit.ly/29HCBAL> and submit online at <http://bit.ly/29yyGSx>

PATIENT OUTCOME
Gonococcal conjunctivitis was confirmed when Gram stain of conjunctival scrapings revealed Gram negative cocci and aerobic culture from both conjunctiva and urethral discharge showed *Neisseria gonorrhoeae*. A polymerase chain reaction test is considered as the gold standard of diagnosing gonococcal conjunctivitis; in this case, smear and culture helped doctors to diagnose quickly gonococcal infection under a microscope and initiate timely treatment. Our patient was treated with a single injection of ceftriaxone, a single dose of oral azithromycin, and symptoms improved 10 days later.

LEARNING POINTS
• Consider gonococcal conjunctivitis when patients present with chemosis and excessive mucopurulent discharge, especially sexually active adults.
• Early diagnosis can prevent blindness and meningitis.

1 What is the most likely diagnosis?
Gonococcal conjunctivitis and conjunctivitis with large amounts of mucopurulent discharge are characteristic signs. Ulceration with subsequent corneal thinning and perforation can develop. Chemosis and eye tenderness are common. It occurs in neonates and in sexually active adults. A thorough social and sexual history helps with diagnosis. Early management can prevent devastating complications, such as blindness and meningitis. Gonococcal ocular infection generally occurs 3-19 days after urinary tract symptoms. The degree of corneal involvement varies, but common types can include marginal corneal melt and subepithelial or stromal infiltrates, or both. The incidence of gonococcal conjunctivitis in adults is increasing, especially with penicillinase-producing *Neisseria gonorrhoeae*.

2 What are the differential diagnoses?
Eyelid oedema can mimic preseptal cellulitis. Epidemic keratoconjunctivitis might also be suspected when only a small amount of ocular discharge is present. Other differentials of urethral discharge with ophthalmic signs include reactive arthritis (formerly known as Reiter's syndrome), and non-gonococcal urethritis with conjunctivitis. In reactive arthritis, inflammatory arthritis accompanies urethritis and mild, transient conjunctivitis (without excessive mucopurulent discharge). *Chlamydia trachomatis*, *Mycoplasma genitalium*, and adenovirus are causative agents of non-gonococcal urethritis with conjunctivitis. In non-gonococcal urethritis, conjunctivitis is usually chronic and without large amounts of mucopurulent discharge—conjunctivitis can develop over weeks or months and might be related to sexual activity or autoinoculation.

3 How would you treat this condition?
The recommended treatment is a single dose of ceftriaxone combined with azithromycin or doxycycline. Treatments do, however, vary worldwide. The outcome after appropriate treatment is generally excellent.

CASE REVIEW A young man with red eye



You can record CPD points for reading any article. We suggest half an hour to read and reflect on each.



Articles with a "learning module" logo have a linked BMJ Learning module at <http://learning.bmj.com>.

Disseminated cutaneous gout

This is cutaneous disseminated gout on the abdominal wall of a man in his 40s.

The patient presented with multiple painless xanthomatous lesions on his abdomen, which appeared insidiously over two years. He was obese, with a body mass index of 39.6 kg/m², and reported a 13 year history of dyslipidaemia, systemic arterial hypertension, and diabetes. He had had gout for five years, with several flare-ups on the first metatarsophalangeal joints and knees. These were managed conservatively using non-steroidal anti-inflammatory drugs, but no hypouricaemic agents.

The main differential for these lesions were cholesterol deposits or crystals of monosodium urate (MSU) secondary to gout. Skin biopsy was performed, revealing an amorphous eosinophilic material surrounded

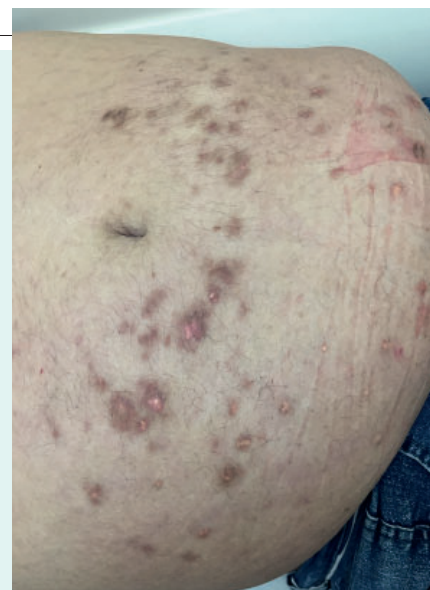
by a lymphohistiocytic infiltrate on the deep dermis, compatible with MSU crystals. At that time, his serum uric acid was raised at 0.65 mmol/L (11.1 mg/dL) (reference range 0.20-0.41 mmol/L).

Cutaneous disseminated gout is a rare, atypical presentation of MSU crystal deposition disease (gout), in which lesions manifest as milia-like papules and eruptions. Its presence implies a greater burden of MSU, thus requiring early treatment with hypouricaemic agents in a similar approach to that in tophaceous gout.

Marina Barguil Macêdo (marina.macedo@fm.usp.br); Ricardo Fuller, Clinics Hospital of the University of São Paulo, São Paulo, Brazil

Patient consent obtained.

Cite this as: *BMJ* 2022;376:BMJ-2021-068263.R1



If you would like to write a Minerva picture case, please see our author guidelines at <http://bit.ly/29HCBAL> and submit online at <http://bit.ly/29yyGSx>

Vaccine hesitancy

Journalists and politicians use the phrase “vaccine hesitancy” to explain why people remain un-immunised despite plentiful supplies of vaccine. The term misleadingly implies that responsibility for a successful vaccination programme lies with individuals. In fact, it is governments that have the power to make vaccines accessible and acceptable. A discussion in *Nature* (<https://www.nature.com/articles/d41586-022-00495-8>) gives pre-pandemic examples of how policy changes (such as developing appropriate messaging and ensuring vaccine availability) have a strong influence on vaccination rates.

Overtreatment of hypertension

Treating hypertension to strict targets risks lowering blood pressure too far. A retrospective study from Spain suggests that this is a real problem. More than a thousand older people receiving antihypertensive drugs were investigated at home with an ambulatory blood pressure monitoring device. Over 40% had levels of blood pressure below 130/70 mmHg—the lower end of the target range recommended by European guidelines (*Age Ageing* doi:10.1093/ageing/afab236).

People with epilepsy had a risk of death nearly seven times higher than people without epilepsy

Psychogenic non-epileptic seizures

A register based study from Sweden compared mortality in people with epilepsy and people with psychogenic non-epileptic seizures against a control group. People with epilepsy had a risk of death nearly seven times higher than people without epilepsy. More surprisingly, risk of death was also raised substantially in people with psychogenic non-epileptic seizures (*J Neurol Neurosurg Psychiatry* doi:10.1136/jnnp-2021-328035).

Stop taking histories

Drawing on his experience of being interrogated by students while in hospital as a patient, a medical educator asks why we still teach medical students to take a history. He reckons that it’s a form of inquiry that objectifies patients, constrains open expression, and restricts the sort of information obtained. Most doctors find they need to unlearn history taking once they begin to work independently, and they replace it with better ways of listening to the patient’s story (*Postgrad Med J* doi:10.1136/postgradmedj-2022-141516).

Depression and dementia

Although depressive symptoms are often linked to the onset of dementia, it’s not clear whether depression is a cause of dementia or simply a prodromal feature. Data from Finland suggest a causal relation. Among

more than 1.6 million people aged 65 or older, a history of depression 15 to 30 years earlier carried a 30% increase in the risk of dementia, even after accounting for educational attainment and marital status (*Br J Psychiatry* doi:10.1192/bjp.2021.217).

Physical activity and cardiovascular diseases in older people

The cardiovascular benefits of physical activity are well established, and a 20 year longitudinal study from Italy confirms its value in older people (*Heart* doi:10.1136/heartjnl-2021-320013). Risks of coronary heart disease and heart failure were around a third lower in people who maintained high levels of physical activity over the course of the study compared with those with low levels of activity. The greatest risk reduction occurred in people who exercised for more than 20 minutes a day.

Music therapy for families with preterm babies

Parents often sing to their newborn babies, which (sometimes) has a calming effect on both parties. Music therapists encouraged parents of premature babies in neonatal intensive care units to do the same. However, a randomised trial found no beneficial effects on mother-infant bonding, parental anxiety, or maternal depression, even though parents liked the intervention (*Pediatrics* doi:10.1542/peds.2021-052797).

Cite this as: *BMJ* 2022;376:o558