

# Dissociative (non-epileptic) seizures: tackling common challenges after the diagnosis

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## ABSTRACT

Dissociative (non-epileptic) seizures are one of the three major causes of transient loss of consciousness. As such, their treatment cannot be left to superspecialised experts. In this article I draw on personal experience to suggest ways to tackle some challenges that commonly arise after diagnosing dissociative seizures, focusing on three issues: “I want to know what is wrong with me,” “I hear what you are saying but it doesn’t apply to me” and “What if I have a seizure?” The suggestions detail both actions and words that may help at a crucial point in the patient’s journey. If handled well, the process can leave the patient better equipped to understand their seizures and to engage in further treatment; if handled badly, patients may be left more traumatised, angry and with additional disability.

## INTRODUCTION

Dissociative (non-epileptic) seizures superficially resemble epileptic seizures or syncope but are an involuntary behavioural and experiential response to distressing internal or external triggers, rather than visible or subjectively perceived manifestations of excessive or hypersynchronous electrical discharges in the brain. Although the diagnosis is sometimes applied to episodes associated with fully retained awareness and responsiveness, a diagnosis of dissociative seizures usually implies impaired consciousness and reduced self-control. Dissociative seizures are one of the three common disorders which, between them, account for over 90% of clinical presentations with transient loss of consciousness.<sup>1</sup> The diagnosis of dissociative seizures is given to about one in five patients attending seizure clinics, and is the diagnosis in up to one in three patients with refractory seizure disorders referred for

video electroencephalogram (EEG).<sup>2,3</sup> In the terms of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, most dissociative seizure presentations fulfil the criteria of functional neurological symptom disorder, which is one of the three most common reasons why patients are referred to neurologists.<sup>4</sup> Given that dissociative seizures often present to emergency services and that medical settings may expose patients with relevant vulnerabilities to potential triggers, these events are encountered by blackout experts and also by general neurologists and by clinicians working in many other medical specialties. Thus most doctors need to know something about dissociative seizures.

This article draws on over two decades of personal experience in the diagnosis and treatment of dissociative seizures. I reference some relevant literature, but the main source for my suggestions is expert opinion. With this proviso, I focus particularly on three questions that often arise once the diagnosis of dissociative seizures has been made. My approach to the diagnostic process itself is described elsewhere and not reiterated here.<sup>5,6</sup>

### “I want to know what is wrong with me”

I usually open the encounter by asking, “What can I do for you today?” This initial enquiry makes no mention of the patient’s complaint, even if I have prior knowledge of it, for instance from a referral letter or the verbal presentation. This opening allows me to listen for how exactly patients formulate their complaint, for instance whether they focus more on their symptoms or the consequences of their neurological problem.<sup>7</sup> The most common reply is a variant of “I want to know what is wrong with me,” that is, a complex question that may be impossible to answer quickly in a way that fulfils the



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**Figure 1** The clinician's most important activity while explaining the diagnosis of dissociative seizures is to listen to the patient.

patient's needs and expectations. However, a satisfactory and credible explanation is extremely important and may make all the difference between a patient whose anxiety level falls and who engages in a treatment process and gets better, and one who is offended, feels rejected or misunderstood and continues to remain severely disabled for years to come.<sup>8</sup>

I try to optimise my understanding of what patients mean with their initial request by deferring the delivery of my diagnosis until I have learnt more about what the patient is looking for and is likely to accept. During a new patient appointment I want to hear patients describe how they first developed their problem and what other healthcare professionals have told them. Even if there is less time (or more information available from their records), I ask the patient to describe their first, their most recent, or a particularly memorable seizure before launching into any explanation. This initial phase of intensive listening is key to understanding what patients want and communicates to patients that I am taking them seriously.

During this opening phase I check that I have all the information needed to communicate my understanding of the diagnosis and proposals for treatment. The opinions of others, scans I have not seen or previous test results of which I am not aware may have little bearing on my ultimate judgement. However, if they are significant in the patient's mind, a prematurely delivered diagnostic formulation could well turn out to be a waste of time. While listening to the patient's account I also consider whether the setting for my explanation of the diagnosis is appropriate: Is there enough time? Would it help to show a seizure recording (if available) after an admission for video EEG? Are relevant people present (for instance, family members or formal and informal carers), or might it be more effective to arrange a better-prepared conversation later? Do I have an appropriate treatment and follow-up plan? It is only after I have satisfied myself

that the time is right that I begin to tell people what is 'wrong' with them (figure 1).<sup>8</sup>

The first part of my account tends to be a statement about certainty. This is important because (notwithstanding the preliminaries listed above) it is crucial, to discuss a *possible* diagnosis of dissociative seizures as soon as this disorder has entered the differential diagnosis and not only when all other possible explanations have been 'ruled out'. For instance, rather than saying, "You have experienced a blackout, I have no idea what caused it," I might say, "You have experienced a blackout, I can't be certain why at this stage, but the commonest causes are fainting, an epileptic seizure or a dissociative seizure," followed by a very short explanation of each mechanism. Mentioning a possible diagnosis of dissociative seizures early greatly facilitates a patient's eventual acceptance of this diagnosis when it has become more certain. However, even before communicating a video EEG-'documented' diagnosis of dissociative seizures,<sup>9</sup> I tend to state that it is difficult to make definitive diagnoses in patients with episodic symptoms, and that it is impossible to travel back in time to explore what exactly caused a particular event that was not captured during any physiological monitoring. This statement is intended to make it easier for patients to voice doubts about my diagnosis (so that I can address them) and to enable them to make sense of the fact that other health professionals—who probably had less information available to them or less expertise—may have previously given them different explanations. I suspect that the honesty evident in this statement ultimately makes my explanation more compelling than would a display of my level of specialisation or seniority.

Giving the condition a name is already implicit in the previous part of the explanation. Some clinicians worry that labelling a phenomenon gives it a medical status. However, when dissociative seizures present to a clinician, they have already become a medical problem whether the clinician is willing to deal with it or not, and naming the condition can give patients an opportunity to start tackling the problem.<sup>10</sup> While naming the condition is crucial in my view, I am less certain which name to use. The term 'dissociative seizure' is defined in the International Classification of Disease, 10th Revision and my current favourite, but it is not widely used or understood by neurologists. In future, patients and professionals may better understand the term 'functional' seizures, and it would link seizures more clearly to other presentations of functional neurological symptom disorder. For now, however, 'dissociative' has the edge over 'psychogenic' (which patients may misunderstand and feel offended by) or 'non-epileptic', which is much too vague, only says what the condition is not, and would cause confusion when a patient never thought they had epilepsy, for instance those who present to syncope services.<sup>11</sup>

In one last preliminary step, I explain how I have reached my diagnostic conclusion (for instance, through hearing the descriptions of the events, or from seeing video and EEG recordings). The purpose of this part of the conversation is to demonstrate that I have carefully considered their problem, and to demonstrate that I have not primarily reached my diagnostic conclusion because of any traumatic events or psychiatric disorders that they may have told me about, or because tests have shown no abnormalities. Dissociative seizures feel predominantly ‘physical’ to those who experience them.<sup>12</sup> Patients often feel that doctors dismiss their concerns too rapidly, and seem to make diagnoses on the basis of their psychosocial history; patients may interpret the happy announcement of a normal scan result as meaning that they must be making up their symptoms.

When I finally move on to my explanation, I first clarify that dissociative seizures are ‘real’ and not produced at will. They do not mean that the patient is going crazy. I then tell patients that dissociative seizures are an involuntary reflex with which the individual deals with triggers inside or outside of the body. I inform patients that most reflexes are quick and ‘automatic’ responses that usually protect the body. Some are present from birth, many are learnt later. The trigger ‘trips the brain up’ and makes it go into a kind of ‘safe’ mode, like a computer that has ‘frozen’ and not working normally. This reflex moves the patient from a moment of perceived threat to a place after the seizure, where they may feel exhausted, upset or embarrassed but are not acutely distressed. Given that each dissociative seizure effectively deals with the trigger (which may otherwise have caused distress), the reflex is reinforced and likely to be used again in similar situations in the future. Unfortunately, however, people lose contact with their environment in their dissociative seizure and cannot exert to control their body. They may think that they are going crazy and become very anxious about their seizures. While dissociative seizures may help the brain deal with a problem in the moment, they therefore cause problems in the longer term.

Framing dissociative seizures as a reflex communicates that they are not wilfully produced, although they may be suppressed. This account is fully consistent with the integrative cognitive model of dissociative seizures,<sup>13</sup> which was developed on the basis of a systematic review of studies examining potentially relevant psychological and psychiatric aetiological factors.<sup>14</sup> Reflexes are generally understood to be rapid, making it more acceptable that dissociative seizures could have been triggered by emotional reactions of which the patient is unaware. The reflex model also allows clinicians to explain how reflexes can be ‘untrained’ and replaced by other responses, providing a rationale for psychotherapeutic interventions.

The explanation of the diagnosis is likely to be most successful if it takes account of a patient’s particular circumstances. For instance, a study based on interviews with patients after the communication of the diagnosis suggested that patients who were aware of significant traumatic experiences in their past found it helpful if the neurologist mentioned that the development of dissociative seizures may be linked to trauma, whereas those unable to recall any traumatic events in their lives could reject the diagnosis of dissociative seizures after the neurologist had strongly linked these to previous trauma.<sup>10</sup> Because of this observation, and acknowledging that trauma is a relevant causative factor in a large proportion of patients with dissociative seizures, I add to the end of my explanation that the development of this protective reflex is particularly common in patients who have experienced significant trauma in the past,<sup>15</sup> although I add that the diagnosis of dissociative seizures is also made in many patients who cannot recall any such experiences. Finally, I pause and ask patients whether my explanation has made any sense to them.

In order to consolidate my explanation, to optimise the patient’s comprehension and to make it easier for them to discuss my account with others, I reproduce a fairly detailed summary of my discussion, using the same words, in a letter that I send to the patient. **Box 1** replicates excerpts of typical letters I may send to patients. I copy in all relevant healthcare practitioners involved in the patient’s care to provide them with the information they need to discuss my explanations in case doubt is expressed. The broad dissemination of the explanation (rather than just the diagnosis) should also reduce the risk of a rediagnosis of epilepsy or of immediate re-referral. In addition to the letter I provide patients with a leaflet explaining their disorder (the COgnitive Behavioural Therapy for Dissociative (Non-epileptic) Seizures CODES trial website has very good leaflets to download for this purpose; [www.codes-trial.org/information-booklets/4579871164](http://www.codes-trial.org/information-booklets/4579871164)). **Table 1** summarises some ‘dos and don’ts’ for explaining the diagnosis of dissociative seizures.

#### **“I hear what you are saying but it doesn’t apply to me”**

My suggestions for the initial explanation of the diagnosis should reduce the number of patients who do not believe that it could account for their symptoms. Apart from the failure to engage in treatment capable of reducing their disability and distress, the adverse consequences of this may include using ineffective (and sometimes dangerous) drugs or non-drug treatments, secondary comorbidities (such as anxiety and depression), and the unending pursuit of costly and potentially harmful further tests.

One strategy that is never likely to resolve this situation is ‘digging in’, by highlighting one’s own expertise and restating the same explanation more forcefully. It is better to step back and analyse what is going wrong.

**Box 1 Excerpts from letters to patients repeating the wording used during the clinic encounter to consolidate my explanation of the diagnosis of dissociative seizures (I address my letters to patients and copy in all relevant other health professionals)**

► Example 1 (diagnosis not certain).

"We discussed that the cause of your seizures remains uncertain. The descriptions I have heard from different people have at times been more consistent with epileptic and at other times more suggestive of dissociative (non-epileptic) seizures. We know that your minor seizures are dissociative because of the symptoms you experience in these attacks and the fact that they were not associated with epileptic discharges in the EEG. However, we have not captured one of your bigger seizures on video or EEG.

It is important to be clear about the diagnosis because the treatment for epileptic and dissociative seizures is different. Dissociative seizures are an involuntary reflex that the brain can develop to deal with triggers inside or outside the body (such as physical symptoms, emotions, thoughts, memories or difficult sensations). These seizures could be treated by exploring whether you could learn to recognise seizure warnings better and by training your brain to deal differently with seizure triggers. Epileptic seizures are caused by abnormal electrical activity in the brain and can be blocked by medications that stop this activity.

Because of the ongoing uncertainty I have asked you to encourage your family and friends to try and video you during one of the bigger seizures. I appreciate that this will be difficult to do but it will help you get the most effective treatment for your seizures."

► Example 2 (diagnosis certain).

"We discussed that you have dissociative (non-epileptic) seizures. This diagnosis is based on what you and your family have told me about your seizures and on the video-EEG recording of typical seizures that I have been able to see. Dissociative seizures are an automatic response of the brain; they are not produced deliberately and do not mean that you are going crazy, and they can get better.

Whereas epileptic seizures are caused by abnormal electrical activity of the brain that can be blocked with antiepileptic drugs, dissociative seizures are an involuntary reflex that the brain can develop to deal with triggers inside or outside the body. Possible inside triggers can include physical symptoms such as pain, fatigue or light-headedness but also emotions, thoughts or even memories. Outside triggers may include situations you find yourself in or things that you pick up with your eyes, ears and other senses. The triggers for dissociative seizures do not need to be truly dangerous or threatening but they may still prompt your brain to go into a "flight or fight" mode. This reflex is often so rapid that people have no recollection of

Continued

**Box 1 Continued**

what started their dissociative seizure. To them, the seizure started "out of the blue."

Once the reflex is triggered, the brain seems to get stuck—a bit like a computer which has "frozen"—when the computer screen is on but the keyboard does not work. Like a computer, the brain may have to "reboot" before it works again.

The best treatment for dissociative seizures is for you to train your brain to deal differently with the triggers for your seizures and the situations in which they are likely to occur. You will hopefully be able to learn techniques allowing you to control your seizure symptoms before your brain gets "stuck" in dissociative seizure mode. It can also help to explore what experiences may have put you at risk of developing dissociative seizures: although these seizures can happen to anyone, they start more commonly in people who have experienced major traumas in their lives.

This treatment is provided by psychotherapists or psychologists. To access this treatment I will refer you to..."

EEG, electroencephalogram.

There are many possible reasons why patients and clinicians may end up not seeing eye-to-eye about dissociative seizures, and the most effective way to resolve this depends on the specific circumstances. Very often, patients need more time to get their head around the explanation. Many have felt dismissed or offended by other health professionals and may need weeks, months or even years to trust another clinician sufficiently to accept their diagnosis and treatment suggestions.<sup>10 16</sup>

Frequently, the communication of the diagnosis is a life-changing event, especially when it involves retracting a previous diagnosis of epilepsy.<sup>10 17</sup> Often patients are left with questions that they may not have felt able to ask during the initial conversation, or which only come to them later, perhaps after they have talked to family or friends. This problem is so common that clinicians should set aside enough time to enable them to prompt patients to ask questions after the explanation. It is also a good idea to offer a follow-up appointment soon after the initial appointment, or to work with other staff members who know what the patient has been told and who can help patients to explore the explanation. Many patients have told me how important it was for them to receive their clinic letter from me, which reiterated my explanation in writing (see [box 1](#) for suggested wordings).

If patients have understood the explanation but are struggling with the stigma associated with it, or if their coping preferences mean that they would rather have no explanation at all, it may be useful to highlight

**Table 1** Communicating the diagnosis of dissociative seizures: experience-based dos and don'ts

	Do	Don't
Preparation	<ul style="list-style-type: none"> <li>▶ Arrange appropriate setting for the communication (time, place, people).</li> <li>▶ Find out as much as you can about the patient (from patient and records).</li> <li>▶ Find out what the patient has been told about the diagnosis.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Spring the diagnosis on the patient in an inappropriate setting.</li> <li>▶ Dodge the communication of the diagnosis.</li> <li>▶ Delegate the communication to the most junior member of the team.</li> </ul>
Explanation	<ul style="list-style-type: none"> <li>▶ Be attentive, engage the patient.</li> <li>▶ Take your time.</li> <li>▶ Demonstrate you understand the disabling nature of the problem.</li> <li>▶ Give it a name.</li> <li>▶ Explain reasons for diagnosis (observations).</li> <li>▶ Provide an explanatory model (like a reflex).</li> <li>▶ Say why it is not epilepsy (if appropriate).</li> <li>▶ Say frequently seen after trauma (not always).</li> <li>▶ Check patient's understanding.</li> <li>▶ Explain how psychotherapy can work (retraining the brain).</li> <li>▶ Explain diagnosis to relevant others (if possible).</li> </ul>	<ul style="list-style-type: none"> <li>▶ Dominate the conversation.</li> <li>▶ Go faster than the patient can follow.</li> <li>▶ Minimise the problem or imply malingering/factitious process.</li> <li>▶ Avoid naming or using 'pseudoseizure'.</li> <li>▶ Only say what it is not or say 'good news'.</li> <li>▶ Say 'the seizures are due to stress'.</li> <li>▶ Continue antiepileptic drugs if pure dissociative seizures.</li> <li>▶ Insist on trauma disclosure.</li> <li>▶ Say 'you need to see a psychiatrist'.</li> <li>▶ Consider or present antidepressants as an alternative to psychotherapy.</li> </ul>
After communication of the diagnosis	<ul style="list-style-type: none"> <li>▶ Reflect on the interaction (do it better next time).</li> <li>▶ Record what explanation given.</li> <li>▶ Consolidate the patient's understanding (letter to patient, leaflet, websites, patient groups).</li> <li>▶ Communicate the diagnosis and explanation to other health professionals.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Document things in writing that were never discussed with the patient.</li> <li>▶ Discharge the patient immediately after the delivery of the diagnosis.</li> </ul>

how the ability to embrace the account offered can help people to move forward.<sup>18–20</sup> Offering follow-up in the neurology clinic reduces the sense of rejection that patients may experience at this point and may help to alleviate patients' concerns about the (additional) involvement of a psychiatrist, psychologist or psychotherapist. Anticipating these concerns, I tell patients what they can expect when they get to see any such professional. The psychotherapists in my department and my colleagues working mental health settings tell me that this helps them greatly to engage patients in the treatments they are able to offer. Telling patients about websites which allow them to explore the diagnosis at their own speed (eg, [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info) or [www.neurosymptoms.org](http://www.neurosymptoms.org)), patient organisations such as FND Hope (<https://fndhope.org.uk/>) or FND Action ([www.nonepilepticattackdisorder.org.uk/non-epileptic-attack-disorder](http://www.nonepilepticattackdisorder.org.uk/non-epileptic-attack-disorder)), about the excellent documentary "dis-sociated" on YouTube (<https://www.youtube.com/channel/UC0h5tSMk6wq2ZiEi8FM-7xg>) or a book with narratives written by over 100 patients with dissociative seizures may help by reducing their sense of isolation.<sup>16</sup>

If patients struggle to accept the reflex explanation because they have not perceived any seizure warnings and their seizures seem to occur 'out of the blue' whether they feel stressed or not, it can help to provide a more extensive account of the complex actions that people are capable of carrying out without ever becoming aware of: for instance, the ability to sidestep a lamp post while being engaged

in animated conversation and walking along a pavement. Many patients who have experienced major trauma are aware that specific reminders of their traumatic experiences, such as smells, shapes or colours—although not inherently dangerous—can bring back explicit memories of what has happened to them. Such patients are unlikely to struggle with the idea that a similar process could trigger a defensive reflex in the brain that operates so rapidly and effectively, that the trauma reminder cannot be recalled afterwards.

Although we have shown that, on the whole, carers are typically more likely than patients to accept a predominantly psychosocial/reactive/adaptive explanation of dissociative seizures,<sup>21</sup> family members or friends sometimes enhance patients' uncertainties about the clinician's explanation. This is why I encourage patients to bring somebody else along when the diagnosis is explained (so I can address any evident concerns of the accompanying person). However, sometimes more work is required to ensure that relevant others do not hinder a patient's chance of recovery: for instance I might provide joint psychoeducation to patients and carers, or include carers' involvement in one or more psychotherapy sessions.<sup>22</sup>

Patients may express their disagreement with the suggested explanation of dissociative seizures in other ways, for instance passively, through increasingly periods of silence. It is important to be aware of this manifestation of disbelief or objection, so that it can be explored. It can be difficult to get patients to express

**Table 2** Suggested actions and things to say for some further difficult moments in interactions with patients with dissociative seizures

	Things to do	Things to say
"So you are saying this is all in my head?"	<ul style="list-style-type: none"> <li>▶ Reflect on your own attitude towards dissociative seizures. If this is what the patient has heard, perhaps this is what you have said.</li> </ul>	<ul style="list-style-type: none"> <li>▶ "I DO think that dissociative seizures are a problem in your head but I don't think that you are making them up or putting them on deliberately."</li> <li>▶ "You only have one brain. Your brain does not have separate sections for your mental or physical health. The brain matches the information it receives from your senses with emotions such as fear, happiness or disgust. Dissociative seizures can be triggered during this process."</li> </ul>
"But the psychiatrist has said I don't have a mental illness."	<ul style="list-style-type: none"> <li>▶ Chase correspondence relating to previous mental health contacts to find out what exactly the psychiatrist said.</li> <li>▶ Establish a working relationship with psychiatrists involved in patients' ongoing care (by talking to them and copying letters).</li> </ul>	<ul style="list-style-type: none"> <li>▶ "Many people who experience dissociative seizures also have mental health problems such as depression, anxiety of post-traumatic stress disorder but many other people don't, and this does not mean the diagnosis is wrong."</li> <li>▶ "I am not sure it really helps to think of dissociative seizures as a mental illness, I would explain them as a kind of reflex response to triggers inside or outside the body..."</li> <li>▶ "Dissociative seizures can be triggered by emotions such as fear, shame, guilt, or sadness but it's a bit like they happen instead of the emotion, and when the seizure is over, many people have no idea what initially triggered them."</li> <li>▶ "Even if a psychiatrist has not identified another mental disorder, retraining your brain with psychological treatment can help."</li> </ul>
"I have had counselling already, but that's all behind me now."	<ul style="list-style-type: none"> <li>▶ Find out about psychological treatment and counselling services in your area, including services from the voluntary and private sectors.</li> </ul>	<ul style="list-style-type: none"> <li>▶ "Counselling is not the same as psychological treatment. Counselling is about attentive listening, psychological treatment is about training the brain to do things differently. Also: the treatment dose needs to be right. Changing the way the brain does something takes time and effort. You will not be proficient at playing a musical instrument after five or ten lessons."</li> </ul>
"What good could talking do?"	<ul style="list-style-type: none"> <li>▶ Establish a contact with psychological treatment services so that you know what patients can expect.</li> <li>▶ Familiarise yourself with common psychotherapeutic approaches so you can explain them.</li> </ul>	<ul style="list-style-type: none"> <li>▶ "Psychological treatment is not just talking. When physiotherapy has worked, it is because the therapist explained to you that you should do something slightly differently. You then practised and your pain or discomfort improved. Psychological therapy is similar. It encourages you to think a little differently about things that you are faced with, and through practice, you may learn to react differently to them."</li> <li>▶ "You are not starting your dissociative seizures deliberately but you may be able to learn to stop them."</li> </ul>
"What about my benefits?"	<ul style="list-style-type: none"> <li>▶ Reflect why patients with dissociative seizures should be less deserving than those disabled by epilepsy, depression or post-traumatic stress disorder? What is the evidence that those with dissociative seizures are more likely to exaggerate their disabilities than those with neurological disorders with demonstrable structural or biochemical changes?</li> </ul>	<ul style="list-style-type: none"> <li>▶ "Of course I very much hope that you are going to get better but benefits are based on your level of disability, not on what the causes of this disability are."</li> </ul>
"What about driving?"	<ul style="list-style-type: none"> <li>▶ Familiarise yourself with relevant regulations. In the UK these are on the Driver and Vehicle Licensing Agency website: <a href="https://www.gov.uk/guidance/assessing-fitness-to-drive-a-guide-for-medical-professionals">https://www.gov.uk/guidance/assessing-fitness-to-drive-a-guide-for-medical-professionals</a>.</li> </ul>	<ul style="list-style-type: none"> <li>▶ "The risk of having a dissociative seizure while driving a car is very low."</li> <li>▶ "However, if you have seizures that could affect your ability to control a car, for instance because they happen 'out of the blue', involve impairment of consciousness or the control of movement, it would not be safe for you to drive a car."</li> <li>▶ "You should be able to drive again once the risk of you having a dissociative seizure has fallen to an acceptable level. You may learn to control your seizures more quickly with psychological treatment."</li> <li>▶ "If you hold a Group 1 driver's licence in the UK (to drive ordinary, non-commercial cars) you are deemed fit to drive when you have not had a dissociative seizure for three months."</li> </ul>

their doubts more explicitly. One effective way of tackling this may be to ask, "How confident are you about the diagnosis on a scale of 1 to 10? Are you around a 3?" Resistance is also implicit in the other common issues captured in [table 2](#), which patients may bring up when the neurologist is trying to explain their diagnosis to them. The table lists these issues and also proposes potentially useful actions and words.

#### "What if I go into a seizure?"

Another reason why neurologists should welcome relevant others during at least one consultation

where the diagnosis is explained is that such an encounter provides an opportunity to discuss how patients as well as carers should deal with the risk of dissociative seizures and what they should do when faced with a seizure.

Although dissociative seizures are rarely associated with severe injuries, they can be. The formulaic recitation of a standard text—especially one originally conceived for epilepsy and including warnings about not driving, taking baths, working at heights or with potentially dangerous machinery and calling an

ambulance if seizures are continuing after 10 min—may cause more harm than good. Many patients with dissociative seizures suffer from low self-esteem and social isolation, and often more of their disability is caused by the avoidance of any activity conceivably involving any element of risk than by the seizures themselves.<sup>19 23</sup>

Rather than enhancing patients' tendency to err on the side of caution, neurologists' advice about living with the risks of seizures and about the acute management of dissociative seizures should encourage patients and carers always to weigh up the risks and benefits of particular choices and to think creatively about small adaptations to their way of doing things that would make them safer. It is important to highlight that not doing things which maintain a person's independence can cause considerable harm. Confidence can wither just like an unused muscle becomes atrophic. Many employers can make small adjustments to how work is done to make a patient at least as safe at their workplace as they would be in their own home. Leisure activities can often continue with minor changes. Working out how unlikely an actual accident would be can often change the perception of risks or injury (for instance, if dissociative seizures have only happened at home or in the evening, they might never interfere with work or leisure activities). If warning symptoms precede the seizures, it may be possible to agree a course of action enabling the patient to make themselves safe. A 'to whom it may concern' letter from the neurologist may facilitate continuation or restoration of both work and leisure activities. Apart from reminding the readers that there is a legal duty to make reasonable adjustments to facilitate the engagement of patients disabled by dissociative seizures in work and leisure activities, such a letter can provide reassurance about the low risk of patients coming to serious harm even during prolonged dissociative seizures, and advice about how to deal with seizure risks and the seizures themselves. Patients and their carers may feel more confident about independent travel outside the home if they carry a card with their name, diagnosis and some very simple instructions telling the reader what to do in case of a seizure. Jewellery alerting finders to a medical condition and offering more information via a contact telephone number may increase patients' confidence and ability to go out unaccompanied. If independent shopping really seems beyond a patient's capabilities, it may be possible for the accompanying person to wait for them outside a shop rather than follow them around everywhere. Confidence may be gained with short expeditions to small shops before patients go off on their own for longer in bigger shops.

Patients and carers are likely to be able to follow this sort of advice more easily if it is combined with a clear plan of action for seizures. Close attention

to dissociative seizures captured by video EEG often reveals how the visible manifestations of seizures decrease or increase slightly in response to changes in the patient's environment, such as the arrival or departure of a clinician or relative. Studies probing a patient's consciousness during a dissociative seizure suggest that most patients retain a degree of ictal contactability.<sup>24 25</sup> This means that seizures can be aggravated by carers who become anxious and distressed during the seizure, and who inadvertently feed these emotions back to the patient. Similarly, the actions and words of emergency care staff can aggravate dissociative seizure states. However, it also means that it is possible to communicate with the patient during the seizure in ways that can help to stop the process. I have seen many persistent dissociative seizures stop shortly after changing the atmosphere around the patient and talking to them very briefly. Having introduced myself, I typically ask everyone surrounding the patient to step back and to minimise physical contact with them. I tell the patient that they are safe but that they are experiencing a dissociative seizure. I assure them that this will stop on its own and that we can talk about it afterwards. I then step back as well and observe the patient from a little distance.

I appreciate that one reason why this approach works so well for me is that my expertise allows me to be quite certain about the nature of the seizure I am witnessing and I am not at all anxious that the patient may be at risk of brain damage from a prolonged seizure, nor am I fearful that they may never come out of their dissociated state. Carers are likely to be considerably more worried.

This is all the more reason to provide them with a clear plan of action best fixed in writing and addressed 'to whom it may concern' (see [box 2](#)). This plan is likely to work best if it is individualised and takes specific account of the patient's particular seizures, psychiatric and medical profile, and the competence of their carers. However such plans have some common elements. The written plans I produce start with a description of the patient's typical event. This ensures that the plan addresses the concerns raised by a particular patient's seizures and allows the reader to recognise what situation the plan should be used for (and, hopefully, to distinguish such situations from other scenarios, such as additional epileptic seizures with different manifestations). My plans particularly emphasise that patients with dissociative seizures can usually hear and sense those around them during their seizures, even if it does not look like it at the time, and despite many patients saying that they do not remember what happens during their seizures. I advise touching the patient as little as possible. The reason for this is that I have learnt that patients may have distorted perceptions of their environment during their seizures and

**Box 2 Common elements of an emergency management plan for dissociative seizures (which should be individualised to particular patients' seizures and circumstances)**

1. Address (eg, 'To whom it may concern'/'Emergency services').
2. Description of the event the plan is intended for. Clarification that dissociative seizures are an automatic response to distressing triggers and not deliberately produced.
3. Approach XXX (the person having the seizure). Say who you are and that they are having a dissociative seizure. Talk to them calmly. Remember that most people can hear and sense those around them during their dissociative seizures.
4. Make XXX safe (for instance by placing a cushion under their head). Remove dangerous objects.
5. Step back and avoid touching XXX once you have made them safe.
6. If breathing too fast, encourage XXX to slow down breathing (breathe in, count to three slowly, breathe out, count to three slowly...). Breathe deeply into your stomach.
7. If talking causes the seizure or breathing to get worse, say you will stop talking but watch from a distance to ensure XXX is safe.
8. There is no need to call an ambulance for dissociative seizures, even if they go on for more than 10 min. Only call an ambulance if the seizure caused an injury, or you think the seizure is different from what is described above.
9. If emergency care services are called: tell them about the diagnosis of dissociative seizures, and show them this document.
10. Dissociative seizures can be made worse by medications used to stop epileptic seizures (such as benzodiazepines).
11. Try to video the seizure (if appropriate/with patient's subsequent consent to store/share recording).
12. Write down your observations (if appropriate).
13. Contact YYY (the author of this plan) if you have any questions about it.

may, for instance, experience what seems like a flashback of a scene of abuse with someone ripping their limbs apart, when all that is happening in reality is someone gently touching their arm.

Another common feature in seizure plans is my advice not to call an ambulance, unless a dissociative seizure has caused an injury requiring emergency intervention. I make it very clear that dissociative seizures typically last much longer than epileptic seizures—commonly longer than 5 min—and that duration alone is no reason to call an ambulance. If a seizure-related injury means that an ambulance must be called, carers can be encouraged to show

emergency care staff the written plan. This may help to minimise the risk of inappropriate interventions from emergency care staff, for instance the administration of benzodiazepines that will probably deepen the dissociative state, prolong and complicate the seizure.

If there is ongoing diagnostic uncertainty—and when patients have consented to this—I also encourage carers to video the seizures, so that I can look at the recordings later. As they record the seizure, it is helpful for carers to talk to the patient to see whether this provokes any kind of response in the carer. Many carers find it extremely difficult to film dissociative seizures, a difficulty that I encounter less often with carers of patients with epilepsy. I suspect that the reason is that carers have to step back and disengage from the seizure process to produce a video recording. The emotional separation implicitly associated with this may actually help carers to provide more effective support to patients during their seizures. Video recording or (alternatively and less good) writing down detailed seizure descriptions is particularly important when patients have (or may have) dissociative seizures with additional epileptic seizures. In such patients video recordings are often not needed just to make an accurate initial diagnosis. In my experience, many patients and their carers continue to struggle greatly with distinguishing different seizure types even after the diagnosis has been made and explained. Repeated discussions of ictal video recordings often reveal that carers categorise seizures quite differently from me. This means that, in patients with mixed seizure disorders, repeated video recording of seizures (and their joint analysis with patients and carers) often continues to be an essential tool for the optimisation of treatment.

Planned medical procedures are one particular scenario in which patients often (and quite rightly) worry about dissociative seizures. The risk of immediate postoperative seizures is well documented.<sup>26</sup> Seizures can occur during dental procedures or after operations involving local or general anaesthesia. Having a dissociative seizure in front of a doctor is particularly dangerous because of the risk of iatrogenic injury or death caused by emergency interventions for erroneously diagnosed status epilepticus.<sup>27</sup> To mitigate this risk patients can be encouraged to share their written plan for dissociative seizure emergencies with doctors planning surgical procedures. Such a written plan will particularly help a clinician if it contains the neurologist's contact details, in case the particular intervention raises additional questions.

### CONCLUDING REMARKS

I have drawn this article quite unapologetically from my personal experience and subjective opinion. My

opinions are obviously informed by the increasing body of research, which has explored the explanation of functional disorders in general and of dissociative seizures in particular, and which is supplemented by research exploring patients' reception of the explanations they have been given.<sup>28 29</sup> However, there are no comparative or controlled studies proving that any one particular approach is better than another. Thus I cannot claim that my proposals represent the best possible approach, although personal experience tells me that my solutions often work. Others may have different experiences and more effective ways of managing these three scenarios.

Furthermore, an article like this cannot possibly be comprehensive. My suggestions are intended to be relevant to the most common ways in which some frequently encountered clinical scenarios unfold. However, I regularly adapt and modify the approaches outlined above in my own practice. No single approach works in every case.

Despite these obvious methodological shortcomings I hope that readers will find this article helpful—either because it gives them new ideas or causes them to challenge their old ones. In addition, the many evidence gaps highlighted by this article will inspire readers to set out and fill them!

### Key points

- ▶ Many doctors need to know about dissociative seizures because they may present in different medical settings.
- ▶ Explaining dissociative seizures as an involuntary reflex response to triggers inside or outside the body is medically correct, widely understood and acceptable to most patients.
- ▶ Early discussion that symptoms may be due to dissociative seizures and a collaborative pursuit of greater certainty maximise the likelihood of patients agreeing with the diagnosis and engaging in treatment.
- ▶ Patients and their families are likely to benefit from a discussion of what to do if they are faced with dissociative seizures.

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