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Could an Interpretative Neurophenomenological Analyses of Seizure Discourse (INASD) contribute towards differential diagnosis of seizures?

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**5% of patients with a diagnosis of epilepsy in primary care
30% of patients considered for epilepsy surgery
up to 50% of people having refractory seizures
are actually experiencing non-epileptic seizures**

NES are not rooted in the brain.

**They have been known about since the
19th Century**

**Differential diagnosis of seizures can
take between 7 and 16 years**

**Medical interventions for epilepsy can be
dangerous for people with NES**

Previous evidence

There is a qualitative difference in the way that people with epilepsy and NES talk about their seizures.

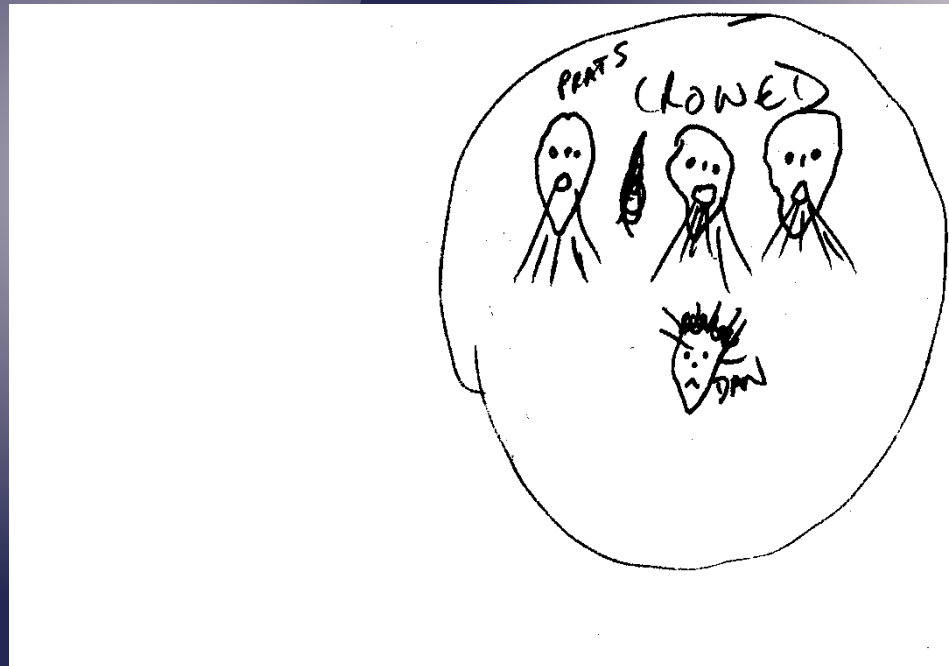
Consciousness has never been satisfactorily defined in the area of seizure experiences

Interpretative Phenomenal Analysis (IPA)

At the heart of IPA is a commitment to cognition and embodiment

IPA strives to unravel 'the relationship between what people think (cognition) say (verbal account) and do (behaviour/physical state)' from the perspective of particular people in a particular context.

Dave was diagnosed with idiopathic generalised epilepsy. He has normal CT and EEG scans.



Autopilot

But er another worrying thing is the black outs.

Yeah, it may not be a fit but - me brain just seems to turn off and I can walk around.

Not know where I am.

Not know where I've been.

Not know what I've done.

I started to feel rough like something's pressing down, pulling down my head or whatever.

It's like being in a football crowd and everybody's screaming at you for attention but you're not able to respond to any of them.

It's basically em, how can I put it? Em, half awake, half asleep and this part - that's where the scream's coming from.

I knew I wanted a couple of onions and a bag of potatoes.

The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me.

Unfortunately, I'd stopped right bang smack in the middle of Beverley Road looking at this lorry coming towards me.

I don't know.

I just came to.

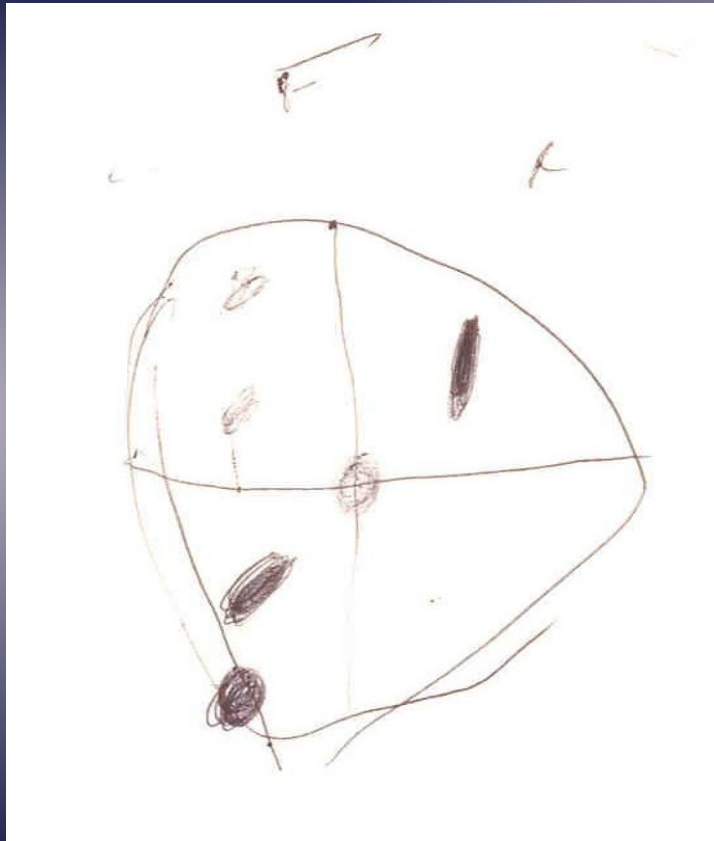
I can move like a rocket when I want to!

Ah, but this is a weird one - carrying a bag of potatoes, yeah.

Autopilot.

I'm in auto pilot.

I'm in auto pilot.



Divide my head into quarters. That's me front, (front of head depicted) that's me right I get headaches there, I get headaches roundabout that area and that area, (areas marked with a black/grey scribbles) these are *intensities*, like the darker it is, the more intense the pain *can* be.

VF: Yeah.

D: It doesn't mean that it *is* going to be *that* intense, but that's how it *can* be intense.

VF: Right.

D: Er, er and there ...

VF: Are they headaches or pains?

D: Headaches and pains, that there could be lower back, sort of there, (shows me the back of his neck) this part, this part here, there, seems to be the only part of my head that seems to be unaffected (the empty quartile).

VF: What made you divide your head into quarters then?

D: Like I said, that seems to be the only part of my head that seems to be unaffected, there- seems to *feel*? Seem to have something at the time.

D: '... I think I'd be oooh, oooh sort of erm [pause] more stupider
erm, more like I said that's sort of – one quart less intelligent.

PC: You mean a bit confused?

D: Yeah– one quart less intelligent.

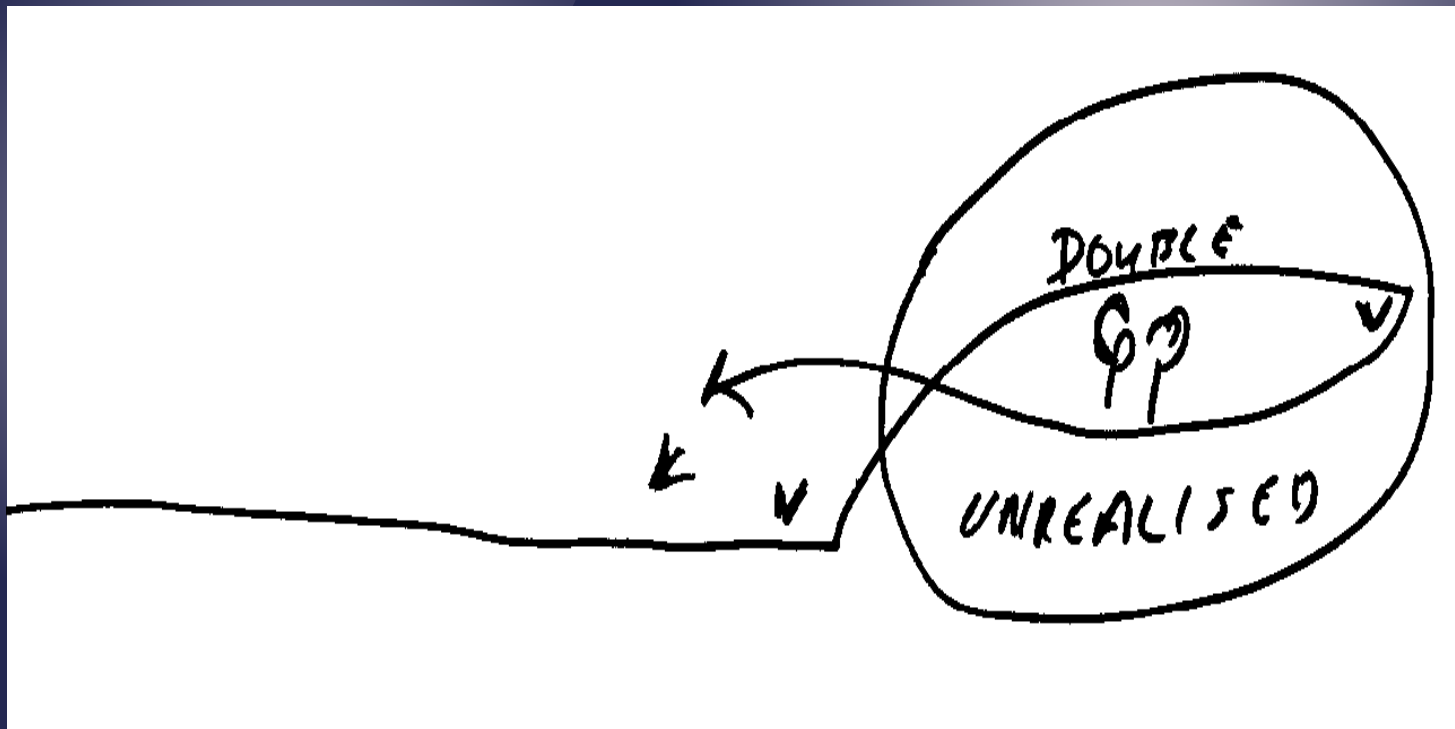
D: There's a D**** inside that's always screaming to be let out no, the
good one.

PC: Not somebody standing beside you?

VF: Where you think there's somebody there but there isn't?

D: Noo, silly, there's the D**** locked inside that's always screaming
to be let out. Please man - let me out.

Vince was finally diagnosed with complex partial seizures with and without generalisation. Scans showed the presence of some old injuries in the right frontal hemisphere and there was correlating epileptic EEG abnormality.



'The whole circle around that there that's me - questioning going in, questioning coming out. But still..... mmm, still unrealised because you don't really feel and if you don't really feel, then the realisation is minimal. No the realisation is, if you feel exactly what is going on – but you don't, so that makes it unrealised. Well that's probably why it's so bloody confusing. You are going in with something and you are coming out and other people realise you have gone in – you come out without any real realisation.'

(Vince, 2008)

At first these feelings were difficult to understand and even harder to explain.

You see I felt that I was drawn away the company I was with and talking to; there was this feeling of being with, but totally apart from. It seemed to me to be quite inexplicable! You see I was there but, indeed, I wasn't. Even now I find it hard to explain the reality of what was going on; it is still confusing to me.

V: And then suddenly this thing came along and I lifted away

VF: Lifted away?

V: Yes that's what it felt like as if I was lifted away. I could *see* the people I was talking to, ... but as the ... em what's the word? – the *contact* seemed to be broken and that's one of the points that erm, I *don't* understand – it didn't seem to make an awful lot of sense.

VF: Did the, the fact that you broke contact with somebody – that didn't make sense to you?

V: What – was the fact that I seemed to have been taken away - and the contact I was making - even though I could still see

VF: You could still see them?

V: Yeah ...but the contact with them was no longer there.

VF: By contact you mean you couldn't speak to them.

V: I mean I was *trying* to speak but as Eileen's just told you, it was mumbo jumbo.

VF: Mmm

V: And the contact had been broken because I failed to realise just what was actually going on.

VF: You failed to realise

V: Yeah

VF: That you were – because you said that you had been lifted – felt as though you had been lifted away.

V: And I couldn't understand the reality of why – you know, what it meant.

it almost felt as if I'd had been somewhere else
you seem to lift up

as if I got lifted up and away and

almost in an empty atmosphere

as if - the atmosphere that keeps you held down.

it lifts you up and you almost feel as if you're floating ...

it's this thing where I seem to lift away

they seemed to have gone further away from you

I'm not me, I seem to have changed

I can't really say whether the thinking is positive or negative

18 months later.....

No, what seems to happen is that, basically I get pretty hot

VF: Hot

V: Yeah, end up with a really stinking headache, which I can't get rid of for at least half an hour

V: I'm wondering instead of, at a point when I'm talking to them, they hear me talking gibberish

VF: That's what you said before, but you don't do that anymore or that does still happen?

Wife: It does happen now and again

V: I don't really notice it

Yeah I remember all that - but that was the weird thing about it I could see, I could see, feel, but not totally understand. Becoming, you know getting on the train or a tube in London and going towards somewhere but going the wrong way,

VF: That's what it feels like

V: But getting on the tube, you're suddenly thinking, I'm going the wrong bloody way, get the tube back, but how often would you actually get on and get a tube back, how often would you actually think like that? That is the thing about epilepsy.

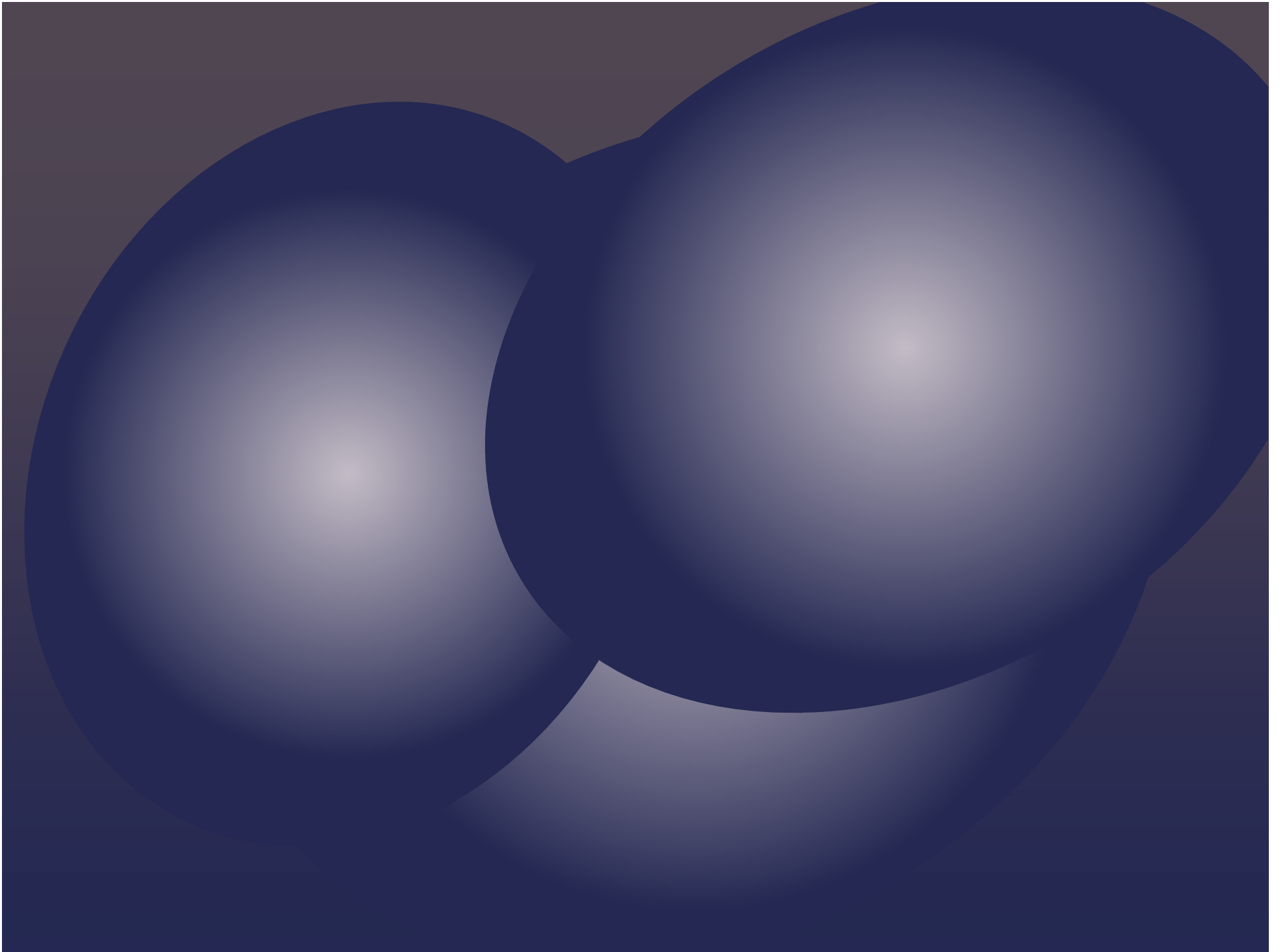
VF: So you still feel a bit like that (the picture)

V: Yeah

V: When that happens, it's like a loss or its like, you come out you going to get in your car, another car, there's another car, the exact same car, put your key in, you wonder why you can't open it.

VF: And that's what its like?

V: Yeah,



The doctors are quite baffled, you know, to why I'm have em *now*.

Cannabis connection

'It's just all like a big question-mark. I feel like I'm on the outside looking in. It feels like it's not me.'

I totally go out when I have em.'

'I can't associate meself with it.'

'I don't have any knowledge that it's coming.'

'So like with these, I would like to know about the details, I will get the names from you again but, erm it's often people are going to deny the cannabis and er, some people, speak about, you know, it started when my brother was murdered but often you don't get that - but the referral from A & E, 'this person came in and had definite tonic clonic seizures, they bit their tongue and so on' and you get on with it. And we don't go through the process of saying, well, are there any recent bereavements, any social things, 'cos we may have ten people waiting outside. And you know, maybe, even what might be straightforward might be not be so straightforward and that's why I am very curious to pull out the notes on these'.

Focal onset epilepsy with secondary generalisation

I don't know, I just, me light goes out.

VF Your light goes out?

G: Yeah, I just don't remember it, you see.

VF Mmm.

G: Until it's [pause] afterwards.

VF But you don't remember then, or you're just there again, you're back again.

G: No, I'm sort of, trying to think, what on earth, what the Hell's happened, what on earth's happened, and how long it had been, I don't know, I don't know anything about that, until my wife explains to us, you know, to the ambulance people, or the people at A and E what I was actually like.

I think you call em absency things, I think you call em, where you have your little flutters, little, well your ears start buzzing, it seems, it can't really-

VF Your ears start buzzing?

G: Yeah, you can't really take in what people are talking to you about.

When I have a seizure it feels like

I have been somewhere else	An electric shock is going through my whole body	Someone just, just blacks me out in a way	I'm on the outside looking in
I got lifted up and away	Daisy dream worlds	Me light goes out	It's not me
I am almost floating	My brain just seems to turn off	I cannot really take in what people are talking to you about	I wonder what is going on
I am not me	My mind goes into overdrive	I can see everything but I've got to concentrate, look straight ahead or, sort of look around	I can't really tell you anything about afterwards
I was drawn away the company I was with and talking to	Blackness for a while	I still hear people talking.	I don't really remember coming round
I was there but, indeed, I wasn't	Everything slows down	I'm frozen	It's just all like a big question-mark
the contact seemed to be broken	Its just 'bumph' to me	It took over me	I'd fell off the chair, you know and obviously gone

'A complete treatment of epilepsy is not just the administration of drugs; rather, it also includes (a) teaching the patient about his brain and its functioning and (b) how the patient's feelings, thinking and behaviour can all be used in the control of his epilepsy.' Fenwick (1991) in (Richard, 1993)

In phenomenology, 'one does not write primarily for being understood; one writes for having understood being'. (van Manen 2006)(p721).

IPA and Neurology

**Tthe potential beginnings of an Interpretative
Neurophenomenological Analyses of Seizure Discourse
(INASD)**

Thank you for listening

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