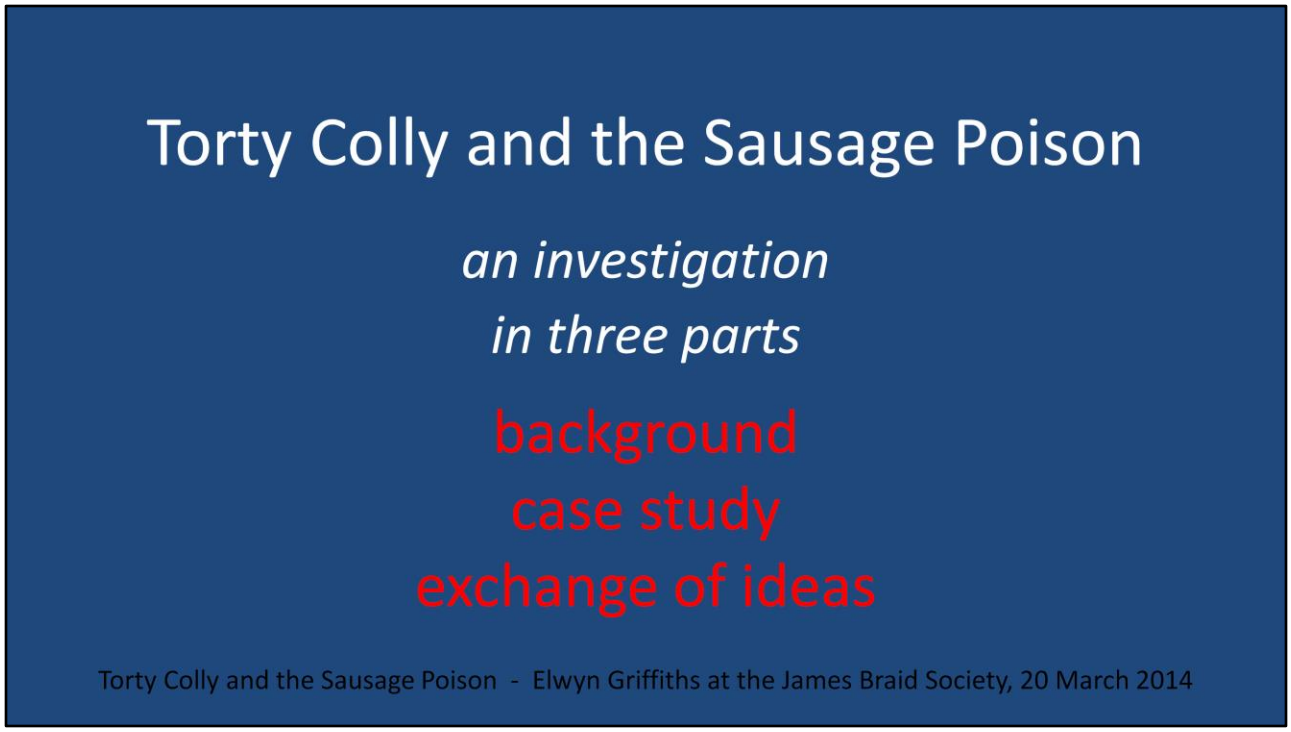
Torty Colly and the Sausage Poison

an investigation

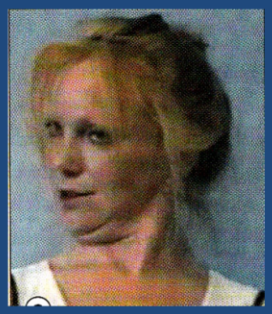
Elwyn Griffiths GQHP, BSc(Hons)
at the **J**ames **B**raid **S**ociety
20 March 2014

I am a Clinical Hypnotherapist in practice in Islington, north London. I am not medically qualified, and I am not a trainer. I am interested in extending the range of conditions for which we can use hypnotherapy.



The choice of title might seem strange, but it is not the strangest thing covered in this presentation.

background



- *what Torty Colly is*
- *what might cause it*
- *the effect it has*
- *treatments*

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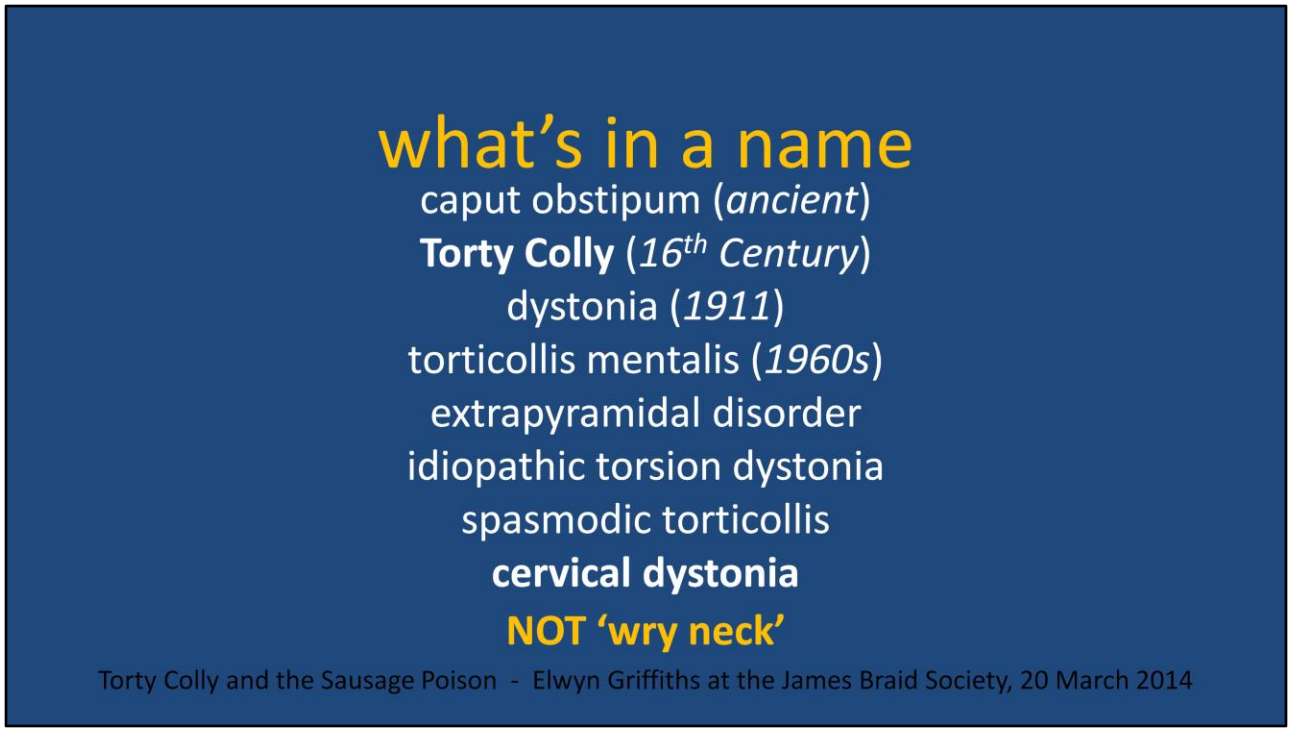
All illustrations of dystonia from Sawle, 1999
Sources are noted with the slides, with details on the last page of this presentation.



I have deliberately chosen a centuries old vernacular phrase for the condition I'm describing because the apparently precise names can mean different things.

The word *dystonia* was coined by Oppenheimer for Scwalbe's 1908 'chronic cramp syndrome with hysterical symptoms'. Torty Colly is **a** dystonia, but *dystonia* can now mean a symptom, or a sign, or a syndrome, or a disease. Usually, it refers to childhood onset idiopathic generalised dystonia (formerly *dystonia musculorum deformans*).

The term *torticollis mentalis* went with the idea (no longer accepted) that the twisting of the head had a purely psychological cause and reflected the historical belief that people suffering from focal dystonias [see below] were mad.
Extrapyramidal disorder, refers to a neurological cause, but can also refer to other conditions.

Idiopathic torsion dystonia is more precise, but can also refer to a syndrome; and the term has also been used to mean *dystonia musculorum deformans.*

Spasmodic torticollis seems to be the preferred term in north America, but it can refer to a symptom, and at the same time not be comprehensive enough and too inclusive.

Cervical dystonia – meaning 'torticollis due to dystonia' seems the best, but incomplete.

Torty Colly is being used to refer to *adult onset primary idiopathic cervical dystonia* [see below].

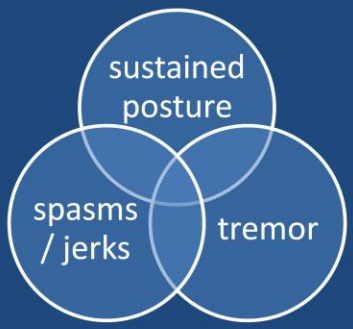
Wry neck is a congenital/acquired musculoskeletal condition.

Sources
Sawle, 1999: Brinn in Moore & Naumann, 2003; Comella, in Warner and Bressman, 2007.

dystonia

"perhaps the least recognised, poorest understood, of the common movement disorders"

- **involuntary** muscle activation
- when at rest **or** in action
- **may** be task-specific



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Essentially, dystonia refers to activation of one or more voluntary muscles (not the smooth muscles) **involuntarily.**
This can be triggered by the initiation of an action, or when there is no such action. And it can be task specific: writing may set it off whilst playing the piano does not. The muscle activation can be any one or more of the physical results shown in the Venn diagram.

Source: Sawle, 1999

Dystonias (such as those in the first line above) are movement disorders, and we can learn something for therapy by comparing with other movement disorders, some of which produce similar effects.
[The yips is a condition suffered by many golfers.]
[Belly dancer's dyskinesia is a particularly distressing writhing of the abdominal muscles.]

Source: Sawle, 1999

neurological conditions

disorder of the basal ganglia

extrapyramidal motor system

surround inhibition

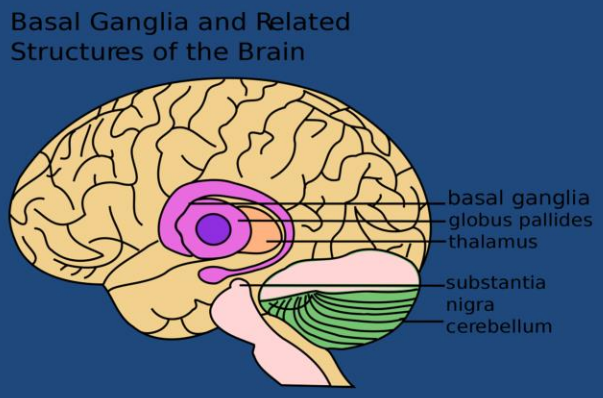

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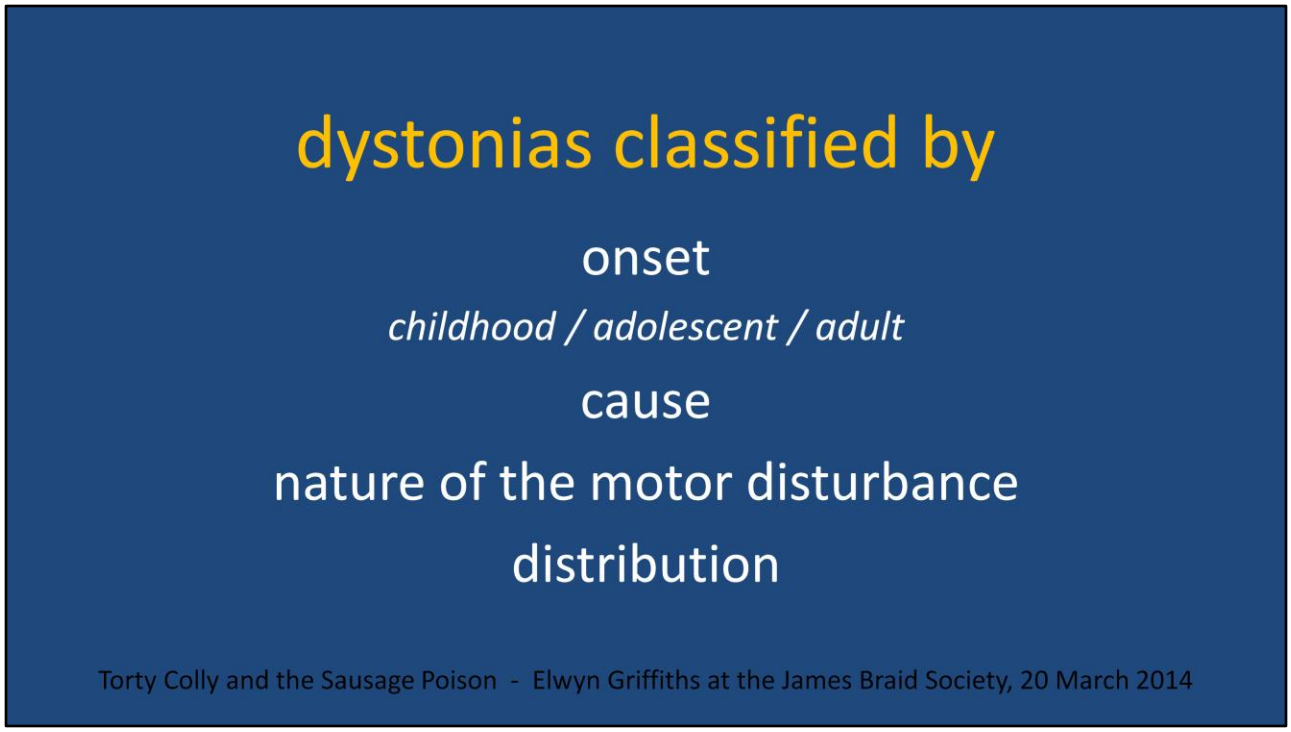
Diagram from
http://en.wikipedia.org/wiki/File:Basal_Ganglia_and_Related_Structures.svg

It now seems generally accepted that the movement disorders are neurological conditions.
The basal ganglia, which coordinates brain activity related to motor actions seems to be the main source of problems.
There may be some disorder of the extrapyramidal motor system in the brain.
And a phenomenon known as *surround inhibition* may be disrupted. It seems that normally when signalling motor action, there is not only a motor nerve activation but also a specific inhibitory signal to the nerves for neighbouring muscles.

Source: Sawle, 1999; Watts, Standaertt and Obeso, 2012.

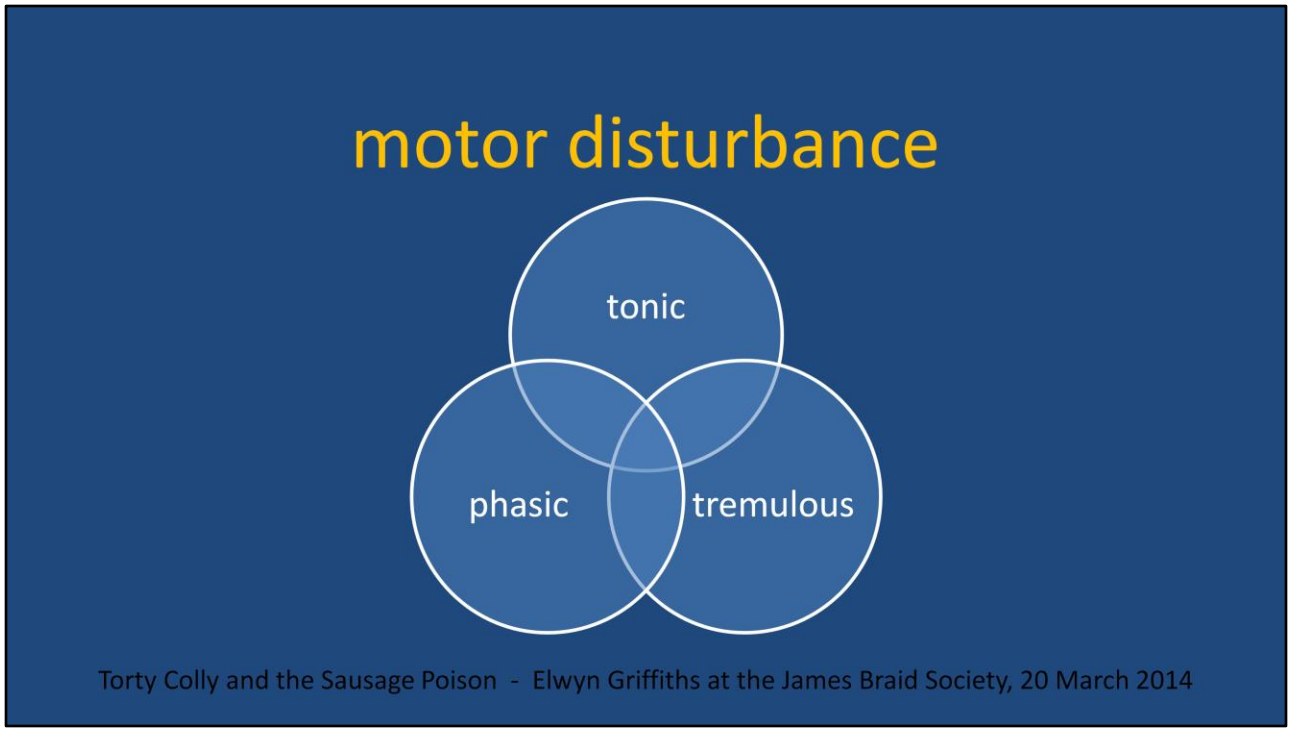


There is a whole range of dystonic conditions.

Source: Sawle, 1999

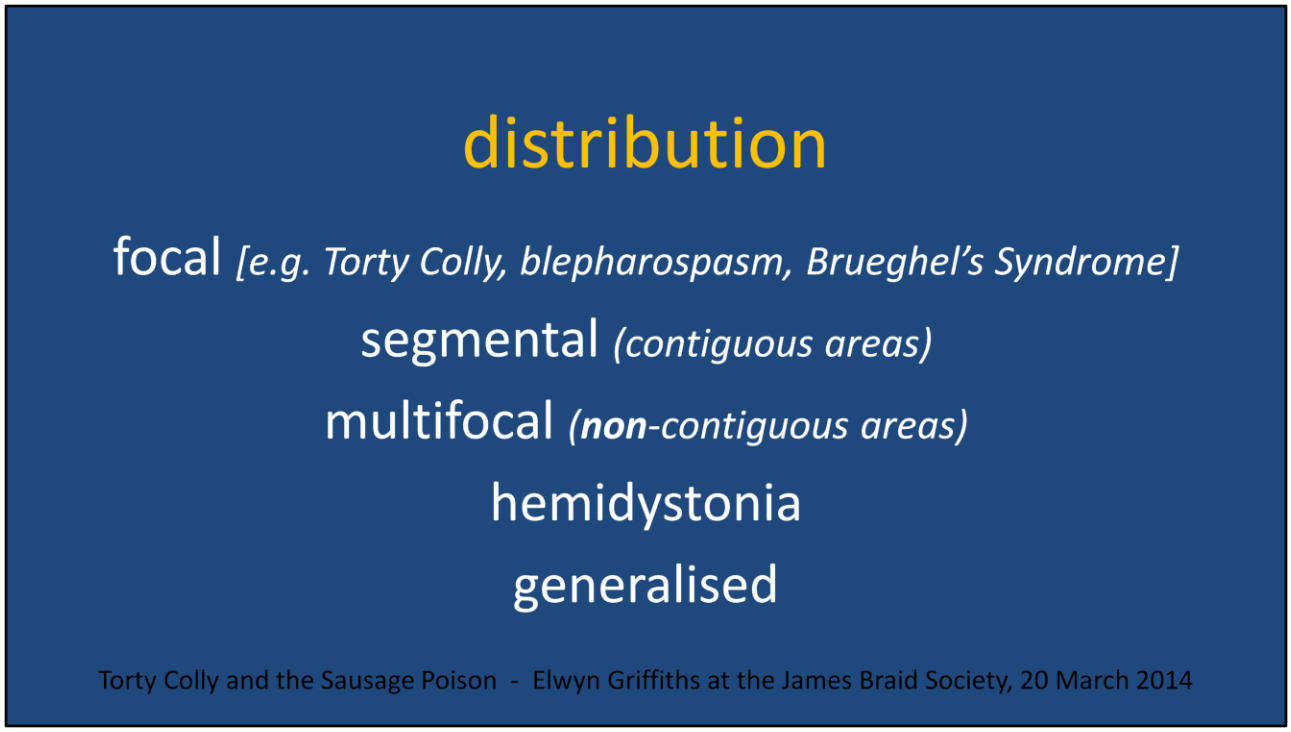
Dystonia may be secondary to a particular disease, such as Parkinison's.
It can be set off by brain damage or by particular medicines.
Many genes which seem to cause or predispose to dystonia have been identified, but the effects tend to come on in childhood.
Nowadays, very few cases are thought to be entirely psychogenic in origin, and the tend to be diagnosed as such only after the other causes have been discounted and the patient has failed to respond to standard treatments.
Torty Colly, and may of the other dystonias are idiopathic – of unknown cause.

Source: Sawle, 1999



In diagnosing a dystonia it will be usual to classify it by the nature of the motor disturbance.
The Torty Colly case I'll describe involved tonic dystonia.

Source: Sawle, 1999



Tort Colly is but one of the dystonias.
A multifocal dystonia might involve the right hand and the left foot. Hemidystonia refers to one side of the body being affected.

Source: Sawle, 1999

prognosis for Torty Colly

progressive deterioration over 2 to 5 years

then stable for many suffers

10 to 20% get period(s) of remission (months or years)

for 25 to 30% it spreads beyond the neck

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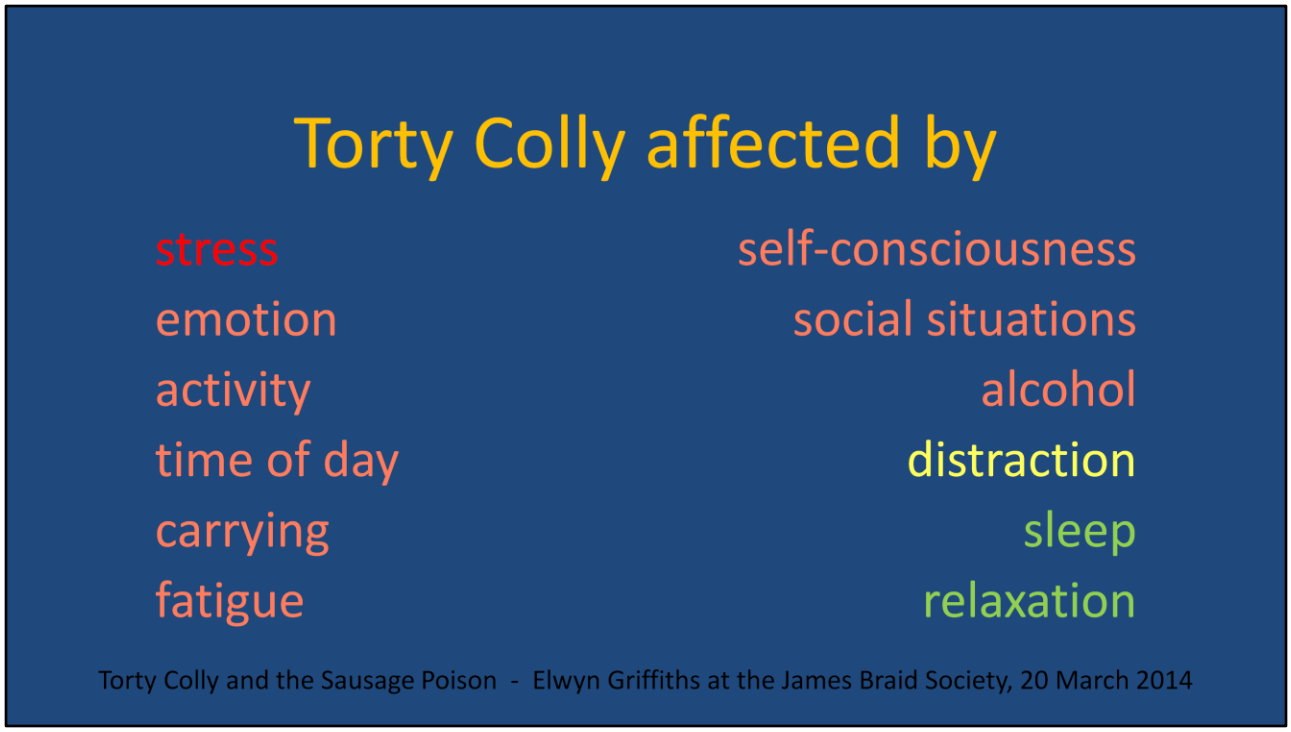
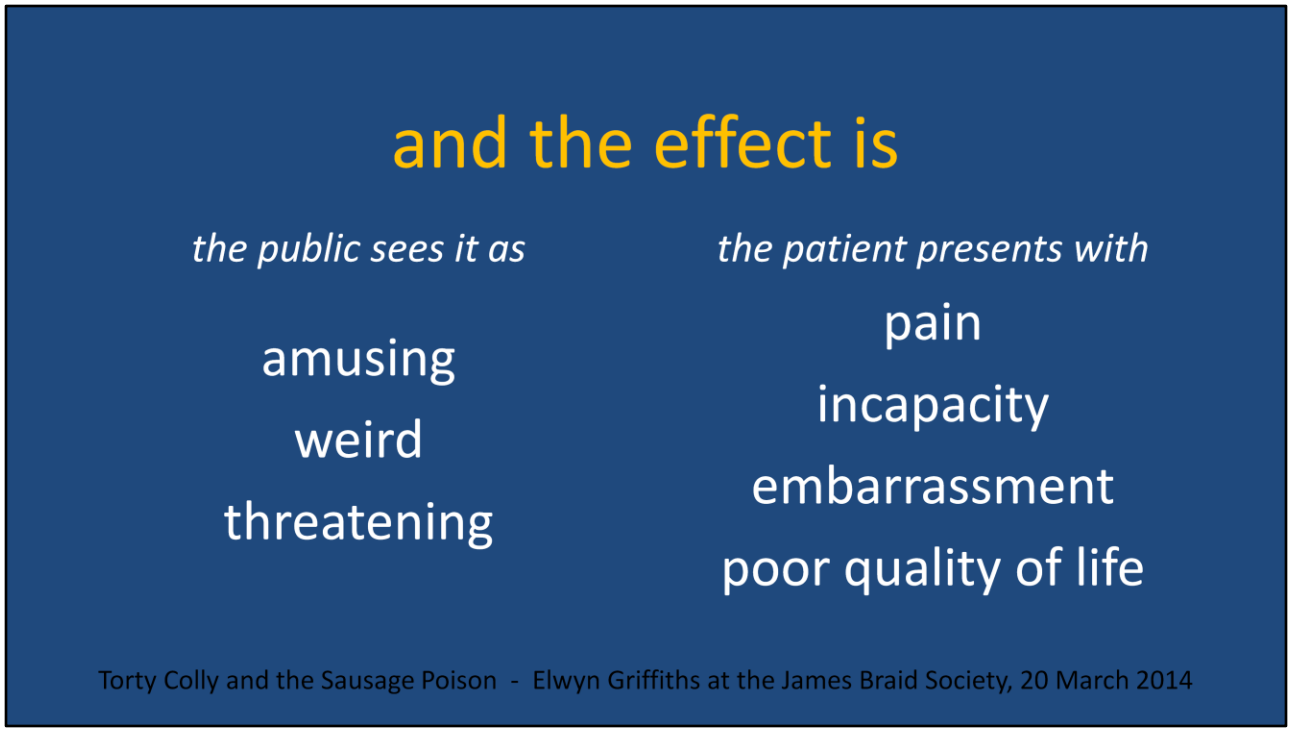
Generally, sufferers can expect their condition to get worse, at least for a while. Whilst for some more muscles become involved, others may get periods of remission maybe for a couple of months, maybe even for years. I think this makes it very difficult to assess the effects of therapy.

Source: Sawle, 1999



Stress seems universally to make Torty Colly worse.
Sleep and relaxation seem to make it better for most, but worse or have no effect for others.
Distraction seems to be mosly neutral, but makes it worse for some and better for others.
All the other items listed make it worse for most sufferers although for some it made it better or had no effect.
I therefore believe it is important to check details with the client.

Source: Jahanshahi, 2000.



70% of patients experience pain.
Functional impairment can result in job loss.
Embarrassment can lead to agoraphobia.
Sufferers can be driven to suicide.

Source: Moore & Naumann, 2003

we can measure the effects

mainly in studies, not medicine

useful in hypnotherapy practice

specific instruments designed for -

- *movement disorders in general*
- *dystonias in particular*

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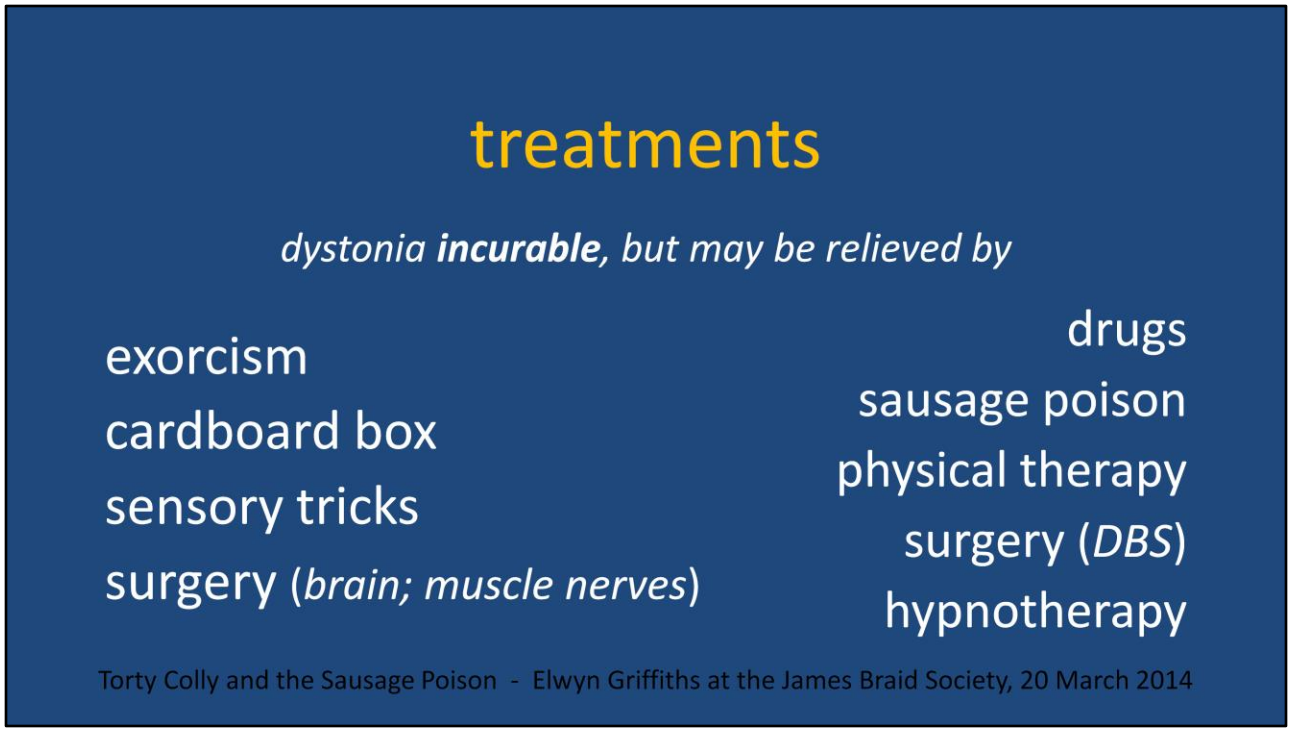
Source: Watts, Standaertt and Obeso, 2012.



Patients have tried exorcism, and one found that a close fitting cardboard box on the head had an “immediate “positive effect””. As Moore notes, “this novel and cheap solution cannot be considered aesthetic or entirely practical”. I suspect the effect was an example of a sensory trick [more below].

Source: Moore, 1995; Sawle, 1999

sensory tricks

a ‘geste’ – *helps many and has no side effects*

CD 6.1. Geste in cervical dystonia.

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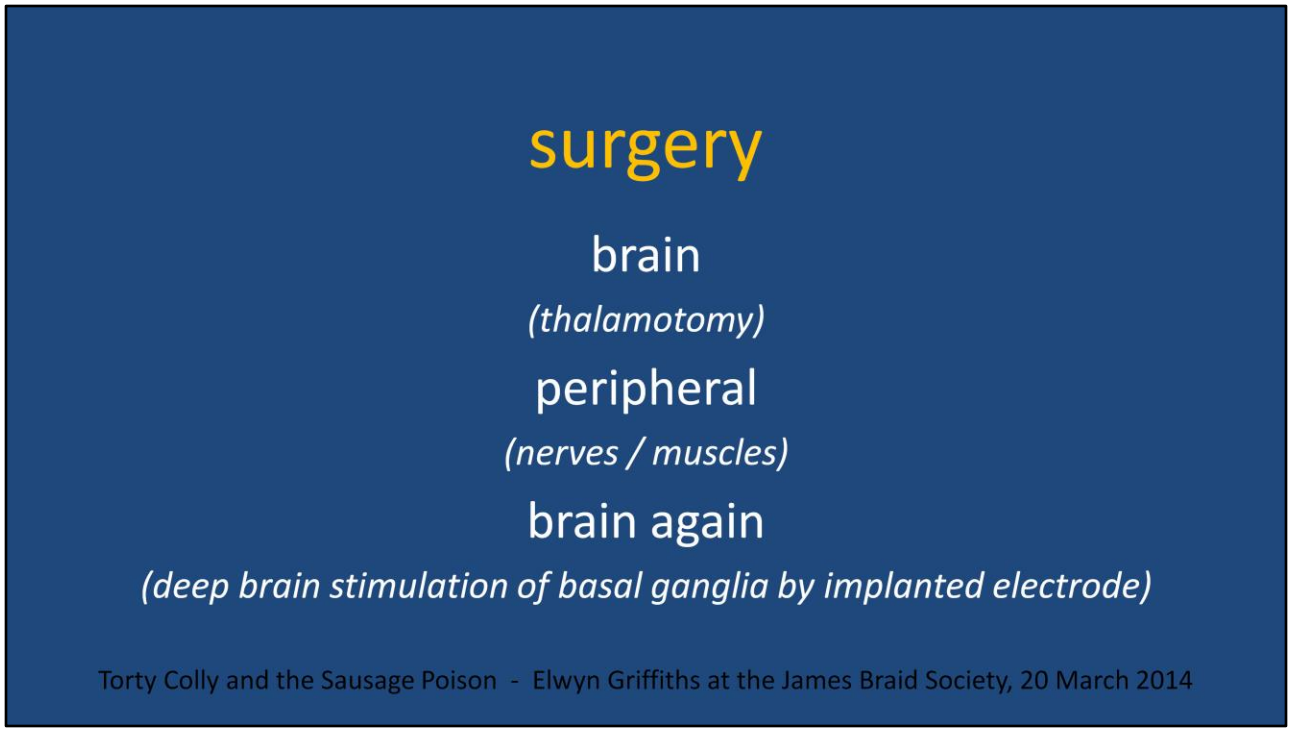
illustration from Sawle, 1999

Sensory tricks [sometimes called gestes antagonistiques] can be effective and are often discovered by the patients themselves. A gentle touch of the chin or head relieves the symptom. In one study nearly 90% of patients reported using a sensory trick. In another study more than half had markedly reduced movement before the hand touched the face, and in yet another study some patients benefited merely by thinking of the geste.

Incorrectly described as a ‘counterpressor’ phenomenon, there is evidence that gestes “initiate a sensiomotor servomechanism that switches off the dystonic drive during the trick”.

Source: Moore and Naumann, 2003.



Source: Sawle, 1999

drugs

effect on nerve function

useful for generalised dystonia

limited number of Torty Colly patients are helped

side effects

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Source: Sawle, 1999

sausage poison

one of the most deadly poisons known to man

1820, 1822 - Justinus Kerner *described, and suggested medical use*

1870, Müller – *coined* 'botulism' *from the Latin for sausage*

1895, Ermengem - bacterium *now Clostridium botulinum*

1944 – neurotoxin isolated

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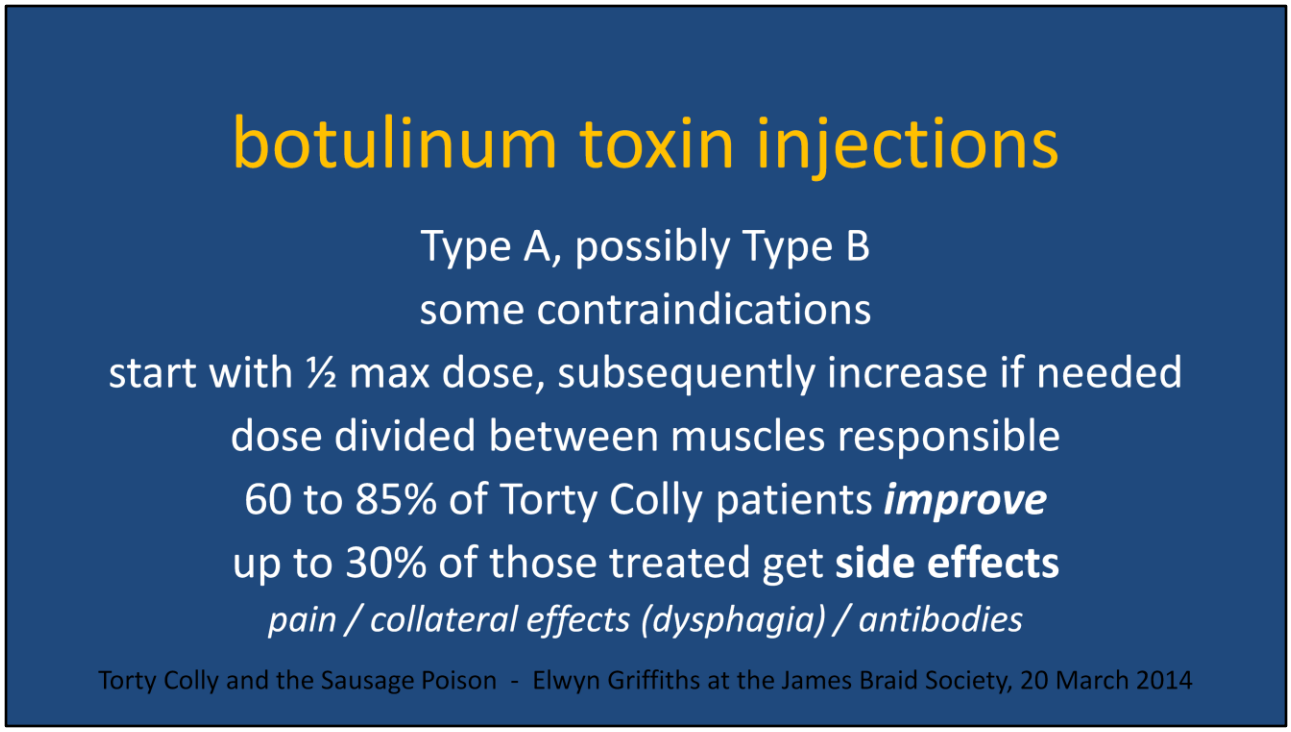
Sources: Nigam and Nigam, 2010; Moore & Naumann, 2003

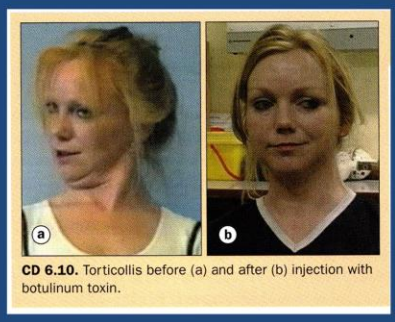


Pain from the injections can last days, but rarely seems so significant that patients decline treatment.
Avoiding affecting neighbouring muscles depends largely on the skill of the doctor, but some patients have had to be put on special diets because of the, temporary, effect on swallowing.
The more treatments patients have, the more likely it is that they will develop antibodies that render the treatment ineffective.

Sources: Moore & Naumann, 2003; Sawle 1999

effects of botulinum toxin

- **reversible** blocking of receptors
- 1 to 3 days to start (may be 2 weeks)
- max benefit after about a week
- benefit declines
- repeat usually after 3 months



CD 6.10. Torticollis before (a) and after (b) injection with botulinum toxin.

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Illustraation from Sawle, 1999.

Benefit can last up to 6 months.

Sources: Moore & Naumann, 2003; Sawle, 1999.

physical therapy

neck manipulation ineffective and dangerous

botulinum injections make physiotherapy possible

muscle training

danger of overstretching the treated muscle

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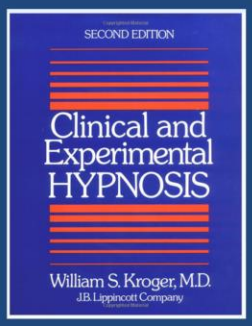
Physiotherapy, accupuncture, osteopathy, chiropractic, neck collar [stiff collars can be broken!] – not consistently effective.
Manipulation risks artery dissection.
Relaxation therapies, including hypnosis, may help up to 50%.

Source: Moore & Naumann 2003

Literature on using hypnotherapy offers some guidance for treating Torty Colly.



hypnotherapy

Kroger, 2008

spasmodic torticollis = 'wry neck',
due to a hysterical conversion reaction
dramatically improved in a single session, but it returns
TC case: sensory tricks enhanced by post-hypnotic suggestion
TC case: 'sensory imagery conditioning' helped public speaking

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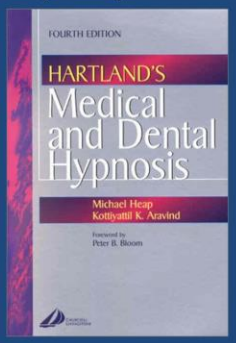
Kroger, W. S. (2008). *Clinical and experimental hypnosis in medicine, dentistry, and psychology* (Rev. 2nd ed.). Philadelphia: Lippincott Williams & Wilkins.

hypnotherapy

Heap and Aravind, 2002

no specific recommendations, but reports that relaxation gave temporary relief –

- Gibson & Heap 1991: relaxation and ego-**shrinking**
- Hoogduin& Reinders 1993: … self-hypnosis …
  … treatment of agoraphobia …
- De Benedittis 1995,1996: … general relaxation,
  ego-**strengthening**, 'differential muscle retraining' …
- Medd 1997: hypnosis included as a relaxation procedure



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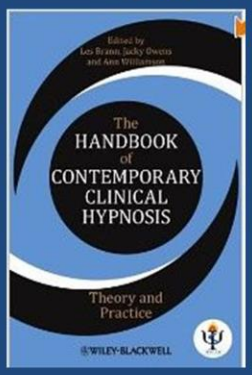
Heap, M.; Aravind, K.K. (2002). *Hartland's medical and dental hypnosis* (4th ed.). Edinburgh ; New York: Churchill Livingstone.

hypnotherapy

Brann, Owens and Williamson, 2012



Benson 1989: hypnotic state alone confers benefits

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Brann, L., Owens, J., & Williamson, A. (Eds.). (2011). *The handbook of contemporary clinical hypnosis: theory and practice*. Chichester, West Sussex, UK: John Wiley & Sons.

The relevant chapter was co-written by Medd and quotes two of Medd's own papers. [see below]

hypnotherapy

Medd, 1999

Medd 1999: includes Torty Colly case study; 3 hypnosis sessions over 1 year for general relaxation, then 3 over 4 months for confidence building; then free of TC and pain

Medd 1999: single case generalised dystonia; hypnotic relaxation produced immobility, then a violent spasm at 13th hypnosis session

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Medd, D. Y. (March 1999). A single-case study of generalized dystonia and hypnosis, with unexpected immobility and an untoward effect. *Contemporary Hypnosis*, *16*(1), 45–48.
Medd, D. Y. (June 1999). Hypnosis with selected movement disorders. *Contemporary Hypnosis*, *16*(2), 81–86.

case study

- the client
- his condition
- his treatments
- approaches I used
- outcomes
- conclusions

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the client

- Male, early 50s, happily married, with 2 teenagers at home
- not born in UK, but contentedly settled here
- previously physically active (running, cycling, squash)
- commuting to work on the Underground
- to a senior, international, management job he enjoyed
- involving meetings with senior colleagues
- and presentations to staff

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his condition

Torty Colly

little pain

serious physical **incapacity** *(unable to drive, difficulty cycling & at work)*

finding travel on the Underground stressful

self-conscious with staff and colleagues

apprehensive of attending a large gathering of wider family

fearing the future

embarrassment

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Torty Colly - adult onset idiopathic cervical dystonia. Head turning to the right with a slight downward tilt and a very slight raising of the right shoulder.
Starts soon after waking. Concentration on a task eased the condition.
No geste used.
Worried about deterioration, impact on ability to work and future financial position.
Long-term problem with embarrassment: largely managed by avoidance and not having caused great difficulty.
Understood that hypnotherapy would not cure the condition.

Botulinum toxin injections started at about 1/3rd maximum dose.
First two hypnotherapy sessions concentrated on taking a detailed history.
Main work was on embarrassment.
Continuing because he finds sessions helpful and he expects further serious life changes.

Sensory tricks and anchoring were not helpful.
Regression, dissociated, to key embarrassing and other events to facilitate reframing.
Mental rehearsal of specific scenarios.
Future orientation, dissociated, to non-specific times 'when problems gone' then looking back, associated, with 20/20 hindsight.
Alternate paths were used to help make decisions about his future consequent on reorganisation at work.

directed at the Torty Colly

session 3

week 2

control room

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The *control room of the mind* seemed likely to be an appropriate way to give him some control over his condition, given the client's background. However, he spontaneously regressed to a childhood incident when he entered a henhouse that had been visited by a fox overnight. The approach was aborted, and although the experience did not seem to be cathartic later sessions suggested that it had confirmed to him that he could revisit difficult situations in his past.

directed at the Torty Colly

sessions 4 & 5

weeks 4 & 6

puppet

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At the first of the puppet sessions he was invited to float above his body and imagine he could control it like a marionette, seeing the strings to his body and limbs, and trying moving them. There were some body movements, and marked jerking of his foot/lower leg. He was then invited to look for the 'fine strings' to his head/neck, see if they were tangled and causing movement when not wanted, and seeing if he could untangle them.

The approach was well received and at the 2nd session it was repeated. When 'untangling' was reached there were jerky movements of his head and shoulders.

directed at the Torty Colly

session 6

week 7

mental

rehearsal

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At the following seeion his Torty Colly had improved enough for cycling, and he wanted to get back to driving.
With appropriate safety caveats, he was taken through an ‘associated’ drive, engaging all his senses.

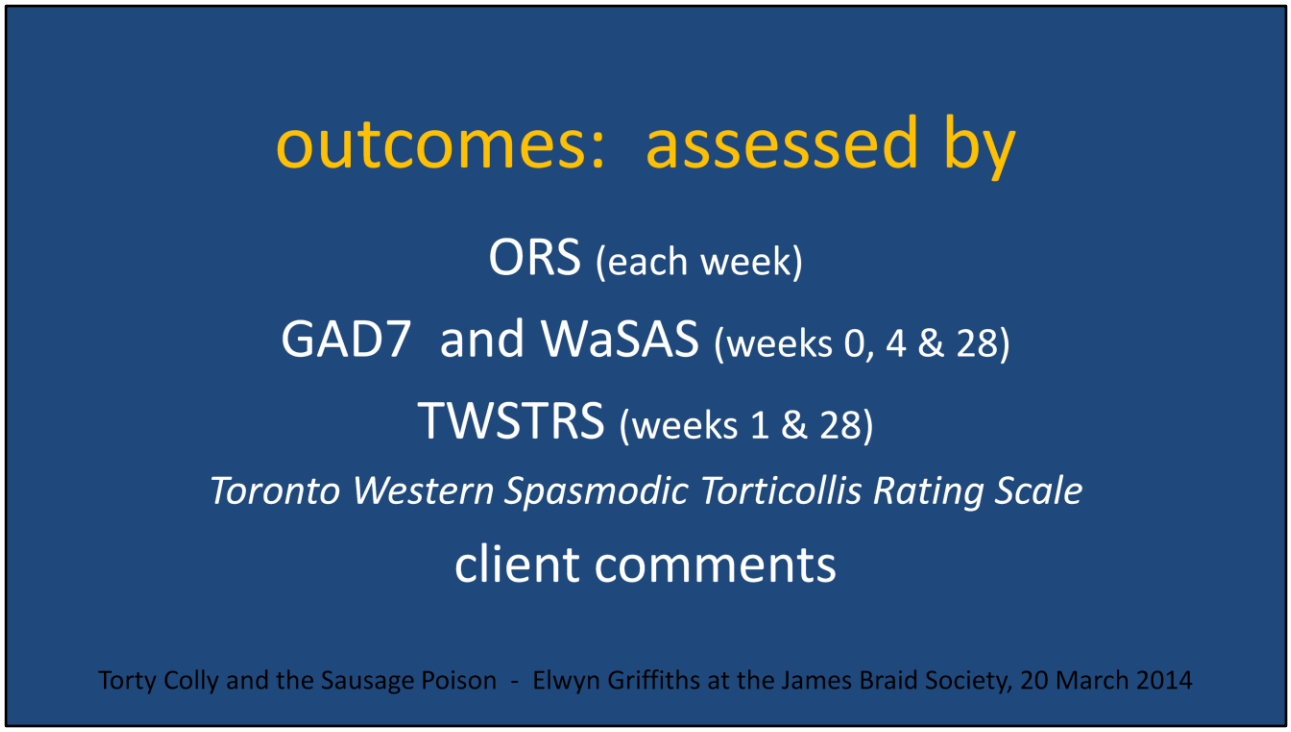
Reducing the frequency of Btn injections and the likelihood of producing antibodies seems worthwhile.

The client had described the effects of his sausage poison injections in such textbook terms that I thought his expectation might be having a significant effect and I explained that some people experience benefit quicker, and that for some the benefit could last for six months.

At the latest session, a week after his Btn injection, he was taken on an 'associated' all senses visit to the Btn clinic and a re-experiencing of the injection. Time distortion was used to take him quickly to his feeling the positive effects of the Btn. He was given posthypnotic suggestions to revisit the clinic in his mind if he felt the need for a boost, and to reinforce the possibility that the benefits of the injection could be felt for longer than the usual 2 to 2½ months.

At the end of the session he reported feeling the benefit of the injection, and wanting to re-experience it in the future.

A planned future session will present an opportunity to check whether he has been re-experiencing this virtual sausage poison on his own.



The Outcome Rating Scale (ORS)
A simple, four-item visual analogue scale designed to assess areas of life functioning known to change as a result of therapeutic intervention.
Developed by Scott Miller. Details at http://scottdmiller.com/performance-metrics/

Generalised Anxiety Disorder Assessment (GAD 7)
A copy can be found at http://www.patient.co.uk/doctor/generalised-anxiety-disorder-assessment-gad-7

Work and Social Adjustment Scale (WaSAS)
See http://bjp.rcpsych.org/content/180/5/461.long

Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS)
Assessing the severity of the dystonia, the disabling effect, and pain. Detail at http://www.kfshrc.edu.sa/mdp/doc/TWSTRS.pdf

Torty Colly reduced, but not a lot.
Incapacity minimised *walks comfortably, cycles, drives* .
Had been very stressed at work in the months before diagnosis of Torty Colly.
Techniques learned in hypnotherapy sessions enabled him to cope with work reorganisation and loss of his job in a positive way.

Embarrassment no longer a problem [not gone]:
made a presentation to a large international staff meeting
attended and organised large family gatherings, and been videoed making a speech
approaching potential employers
at ease travelling on Tube

Facing his uncertain future with equanimity/excitement:
set up own company
longer term, possibly return 'home' when his children go to University there.

conclusions

- uniqueness of client
- amelioration not cure
- problems on different levels
- multi-disciplinary task
- hypnotherapy underutilised?

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Another case

This is an interesting report because the sufferer is a hypnotherapist and has used hypnosis to help with Torty Colly. Points to note are –
temporary relief with osteopathy
the side effects of medication
the side effect of considerable pain with Botulinum neurotoxin injections
the eventual recourse to surgery and the gradual effect of deep brain stimulation.
The latest news is that the next step in Sophia's story is that she is being fitted with a rechargeable battery for her DBS on 9th April. She has asked to have this surgery under local, instead of general anaesthetic "as I know that I can relax myself very well!".
Elwyn Griffiths
20 March 2014

Dystonia – Spasmodic Torticollis

by Sophia Steeden HPD, Dip.H, Dip.NLP, SNHS Dip & Cert.SM ~ Hypnotherapist in Whitchurch, Hampshire

Dystonia Spasmodic Torticollis (DST): a condition whereby the brain sends a message to the neck muscles instructing them to turn right 24hrs a day, 7 days a week, 365 days a year (366 in a Leap year). "Yes!" I thought, when I was finally given a diagnosis back in 2002, "Finally I understand what this annoying, painful, jerking and rotation of

my head is!"
My relief was short-lived. Whilst investigating this condition, it seemed to me to be doom and gloom on every website I visited, without a solution or cure. However, I made a decision there and then: I was going to conquer this condition, or at least take total control of how it would feature in my life. Saying this was easier said than done at certain times. Sometimes the pain was unbearable. The pulling to the right would cause my neck, shoulders and back to be pulled out of line. I'd make frequent visits to the Osteopath – followed by 24-48 hours more discomfort – for it all to settle again!
The first medication prescribed to me after diagnosis, was in tablet form. The week that followed was hideous. The tablets made me feel spaced out – as though I were merely an observer of life. Life began to feel as though it was simply happening around me. I stopped taking them very quickly, as a working mother I needed to be focused on what I was doing. I then pursued the route of 'Botulium' (Botox) injections, but soon realised that I would have to fight as my local PCT refused my treatment. These injections paralyse the muscles that were pushing/pulling my head to the right, which would alleviate the pressure in my head and on my shoulders and back. In the interim – and due to very kind family members – I paid to see a consultant privately for these injections at a private clinic in Havant, Hampshire. It took quite a few months to get the correct dosage and area, but they worked. These injections weren't cheap, so I kept fighting for treatment on the NHS, and eventually won my battle in January, 2004. It would be the same consultant, but at Southampton Hospital.
My work during this time was office based and I was finding it increasingly uncomfortable to work at a desk. Determined not to let this condition beat me, I put my mind to identifying an alternative career. I wanted to do something that would allow me to work from home, but something that would also challenge and satisfy me. Hypnotherapy sprang to mind; I had successfully used hypnotherapy to give up smoking, and had also used it to help me with my condition. Hypnosis is a great relaxation tool, and also works well for pain relief and filled me with confidence and a positive attitude toward life with this condition. I found an accredited course, signed up and qualified in 2009.
I can honestly say I have never felt so good about life and myself in general. I believe it's because of this knowledge that I was able to pursue and undergo the Deep Brain Stimulation operation in 2012, without fear or hesitation. It will be a year 22nd August 2013 since the operation – a year during which, gradually, my head is straightening. Hopefully very soon, it will look and feel totally normal! Also, I've gone a year without Botulium injections, which would previously have rendered me crippled with pain. Although I am still having times of discomfort (I don't like to focus on the word pain), they are becoming less. It's truly amazing what we can achieve if we set our mind to it!
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