

THE 'FATS' OF LIFE CONCERNING WEIGHTY ISSUES IN ARACHNOIDITIS

This article aims to tackle a difficult aspect of chronic illness: weight gain. Sorry about the dreadful title: but it's an attempt at levity in this heavyweight topic. (I'm trying to live up to the 'fat and jolly' epithet!)

As if we didn't have enough on our plates, now we have to contend with increasing girth and vanishing waistlines!

We have to confront the uncomfortable reality that society is extremely 'fattist'. Being overweight equals being viewed as greedy and lazy (and often, stupid).

Society nowadays is obsessed with the 'body beautiful'.

Of course, arachniacs would settle for the 'body functional' because we know all about living with a body that doesn't work properly.

I have often thought about going to the Body Shop and asking for a new one, a body, I mean. I guess the men in white coats might appear to drag me off if I did!

Seriously though, putting on weight can really knock one's confidence.

Not only that, but clothes no longer fit, and unless you are a real fan of shopping (getting changed in communal changing rooms is a No-no for me) then this is a bind.

We mustn't forget the other very real problem with weight gain: it makes things worse for our backs, our digestion, our legs, our burning feet. Major weight gain may impair our mobility and cause a knock-on effect of further weight gain.

Not only that, but being seriously overweight (obese is the unpleasant term) brings with it increased risk of Type 2 Diabetes, heart disease, stroke, gallbladder disease.

It is second only to smoking as a cause of death.

WHY?

Basically, there are 4 main reasons for weight gain in arachnoiditis:

1. reduced mobility
2. medication
3. excessive eating
4. fluid retention

not to mention: a combination of all four!

Of course, in women, there are 3 hormonal stages at which weight increase occurs: during puberty at onset of periods, during pregnancy and during menopause: so if you are around the menopause, then this could well be an additional factor to take into consideration.

Some folk, like myself, will be feeling virtuous for stopping smoking: until we hit the downside: theoretically, we shouldn't be gaining weight but we jolly well are (well, perhaps jolly isn't quite the right word!)

THE CULPRITS:

Medication may cause fluid retention, and may well interfere with appetite; some, such as amitriptyline and morphine, are known to cause a 'sweet tooth': sugar cravings.

Gabapentin reduces energy expenditure and induces carbohydrate intake.

Drugs which cause thirst, such as antidepressants, may lead to increased drinking of high calorie beverages, which of course adds to weight increase.

It is of little help to learn that the effects of drugs such as amitriptyline are in fact reversible, because most of us are on them long-term for the foreseeable future.

I suppose one might consider a change to an SSRI (e.g. Prozac) but these are less effective in combating nerve-related pain.

Clonidine is another drug which can cause weight gain. It may affect appetite and can also cause taste changes.

NSAIDs (anti-inflammatory drugs such as brufen) can cause fluid retention which does not respond to water tablets (diuretics).

The other problem with medication is that some types can cause indigestion which may encourage us to 'nibble' between meals to relieve the heartburn.

COMFORT EATING:

There's no doubt that a lot of us are 'guilty' of this 'sin'. And who can blame us? After all, we have a lot of trials and tribulations. We even have some scientific data to back up our eating chocolate: it is thought to help reduce pain and depression.

So if we sneak a little (or a large!) nibble of something sweet, we can consider it 'therapeutic'. As always, though, there's a price to pay, and in our case, it isn't pounds and pence but pounds and ounces (or kilos as we should say nowadays).

Once in a while, there's no harm in treating ourselves. We just can't afford to let it get to be a habit.

OPTIONS (no, not the hot drink in a sachet!*)

There is a basic rule in weight loss, as the Dean of my medical school was fond of saying: the intake must be less than the energy expenditure. This sounds ridiculously simple but is in essence true.

Of course, that was easy for a stick-thin Professor of Medicine to say!

Being an arachniac is not so simple.

We can't increase our exercise to a level where significantly increased calorific expenditure occurs, because if we do, hey presto, we are slap bang into a flare up and back to being immobilised by pain.

Our medication is a two-edged sword: take enough to relieve the pain, and the weight goes on.

So regrettably, we are left with 'dietary manipulation'.
(* though they are a good substitute for hot chocolate)

WHAT CAN WE DO ABOUT IT?

Do we really have to brace ourselves for endless self-control, missing out on 'goodies'; life is hard enough as it is!

Well, the bottom line (pardon the pun!) is that prevention is (as always) better than cure.

This means we need to be vigilant about the strength of the pound (and I don't mean sterling!)

SHORT CUTS TO CURB 'INFLATION'?

What about these great diet aids, they sound really ideal. They've even been researched!

Hold on a minute though... on closer inspection and having investigated this 'research', yes, it has been done, but no, it doesn't show any conclusive evidence that it actually WORKS!

So are these diet aids useless or is it just the medical profession being 'sniffy'?

It is fair to say that the 'diet world' is brim-full of unsubstantiated and sometimes outrageous claims that take advantage of vulnerable people.

It is a minefield.

Basic rules: don't consult the staff in a health food shop: they don't have the relevant knowledge of the benefits and risks of the different options.

For nutritional supplements: ALWAYS CHECK WITH YOUR DOCTOR ABOUT THE ADVISABILITY OF TAKING THESE.

DANGER SIGNALS:

The main culprits which are dangerous practice include:

1. diuretics (water pills) taken to lose weight
2. laxatives: in excess to attempt weight loss
3. diet pills

The first 2 options can cause serious problems with salt imbalances and malabsorption of important nutrients.

THE 'DIET INDUSTRY' THAT FEEDS ON OUR NEED TO BE SLIM

Watch out for these terms in some of the claims made for products of the diet industry:

- fat burner/blocker/trapper
- quick and easy weight loss
- secret or ancient formula
- weight loss breakthrough/scientific breakthrough
- weight loss without dieting/exercise
- new revolutionary method
- 'secret'/'magical'/'synergistic' ingredients

DIET PILLS AND POTIONS: ARE THEY ALL HOCUS POCUS?

1. HCA: (in *Garcinia cambogia*) touted as 'an all natural, caffeine free, dietary food supplement' which can 'enhance the body's metabolism'. Usually found in preparations which contain other ingredients including herbs such as Bladder wrack, which contains iodine (effects the thyroid gland*) and Gingko (note if taken with NSAIDs, there may be

a risk of bleeding).

Patrick Bird Ph.D in 1999, commented

"You may not want to lay out hard earned cash for these HCA diet products"

He points out that often the advised measures given alongside the supplements, such as reduce fat intake, drink plenty of water, eat lots of fibre and get plenty of exercise, will, by themselves, lead to weight loss, regardless of the use of the HCA!

An article in the Canadian Journal of Applied Physiology in December 2000 noted

"To date, there is little or no evidence supporting that (HCA is) of any value for weight loss in humans."

So far, there doesn't seem to have been any drug interactions between HCA (alone) and other medication, but note, if it is in a preparation with other ingredients, one must take into account possible adverse effects and drug interactions.

2. EPHEDRA/MA HUANG: note: preparation of ephedra have been withdrawn in the USA because of severe adverse effects: including fatal heart rhythm abnormalities and heart attacks.

It was in the product known as "phen-fen"

3. ST. JOHN'S WORT: if not suffering from depression-related weight gain or significant food craving, then this may not be helpful. It interacts with other commonly used medication.

4. CHROMIUM PICOLINATE : hype claims this is a fat burner and a muscle builder. The warning bells should be ringing! This is a prime example of false theories, poor and unsubstantiated research being used to set up a 'weight loss panacea'.

5. PYRUVATE: no proof of weight loss

6. GUARANA: touted as a metabolism booster and fat burner. Main ingredient is caffeine, so save your money and have a cup of coffee instead.

7. PHENYLPROPANOLAMINE (PPA) active ingredient of over-the-counter pills in the USA (Dexatrim, Acutrim) and may be available via the Internet. Now banned by the FDA (US regulatory body) due to serious side effects

8. HERBAL WEIGHT LOSS TEAS/SENNA: basically, these are designed to cause herbally-induced diarrhoea, but they can cause serious adverse effects, Laxatives don't work on the small intestine, where calories are absorbed.

9. CHITOSAN/CHITIN: a fibre from the shells of crabs and other crustaceans (note: not suitable for those who are allergic to shellfish!) claimed to 'trap fat', which is unsubstantiated. A study published by the European Journal of Clinical Nutrition showed no correlation between chitosan and weight loss.

10. KELP: as with Bladderwrack* this seaweed based supplement contains iodine which affects the thyroid gland; note that there does seem to be a link between myelogram dyes and thyroid disorder, so if you are considering taking this supplement, you must check with your doctor first. It aims to speed up the body's metabolism thereby burning up excess calories.

Herbal preparations which claim to act as diuretics should also be considered with great caution as there is a risk that they can cause serious mineral deficit, especially potassium and this can impact on heart rhythm.

ORLISTAT: XENICAL

This treatment has recently become available in the UK, for a select group of obese patients. It causes a slow but sustained weight loss when used in conjunction with dietary modification and exercise protocol.

The clinical guidelines state there has to have been some weight loss in the preceding 3 months, for a patient to be considered for this treatment. Note: the Xenical absorbs 30% of the fat intake in the diet, and one must remember, it also absorbs other important nutrients, especially fat-soluble vitamins A, D, E and K.

TO DIET OR NOT TO DIET?

I always loved the Garfield cartoons with the lovable roguish stripey ginger cat who really did ADORE his food!

One in particular sticks in my mind: Garfield's definition of a diet:

" 'DIE' WITH A 'T'"!

I can relate to that! How is it that when I was slim, I didn't fancy chocolate biscuits, but now that I've expanded, I can't face the idea of NOT being allowed them!

The good news is that all the 'fad' diets don't work in the long term (well, around 95% of them don't).

The not so good news: we have to moderate our diet on a long term basis: re-educate our palate and cut out too many 'nicies'!

However, it isn't so bad these days because there are so many 'diet' food products which really do taste more or less like the 'real thing'.

So get stuck into the low cal version of your favourite food and feel suitably smug when you read on the package that it is very low fat etc.!

Here's a few examples:

- Semi/skimmed milk (personally, I think the skimmed tastes like water: but the semi-skimmed is OK) you might want to look for special types with added calcium if you are a woman around or after menopause
- Very Low fat yogurts
- Low fat cheese
- Low fat Weight Watchers ready meals
- Low fat puddings including ice cream
- Sugar-free sweets
- Sugar-free drinks
- Low calorie cereal
- Tinned fruit in juice rather than syrup
- Low fat crisps

Note that salad stuff and raw veg. make a good snack and celery actually takes more calories to digest than it provides!

Fruit is as you no doubt know, an excellent food, and if you want it to taste more sugary, then try the dried versions. (keeps you regular too!)

OUTPUT?

The other side of the equation of input and output is exercise.

Unfortunately, this is not our strong point, so to speak.

However, we really do have to literally 'pull our weight': we have to find a way to maximise our energy expenditure within the limitations of our illness.

This means that, just like the diet, this is an ongoing, everyday matter, the establishment of habits for a lifetime.

Don't forget that exercise brings a range of benefits:

It can reduce joint pain and stiffness and increase flexibility, muscle strength, and endurance as well as helping with weight reduction and it tends to contribute to an improved sense of well-being.

The ideal is to track down a skilled doctor, such as a Rheumatologist, who is knowledgeable about the medical and rehabilitation needs of people with conditions that are similar in their course to arachnoiditis: e.g. inflammatory arthritis.

Then you would be referred to work with a physiotherapist also familiar with the needs of people such as those with arthritis, who can design an exercise plan for each patient.

NOTE: rest and relaxation is an important part of an exercise regime.

The rule for exercise is little and often rather than a major work out once a week.

TYPES OF EXERCISE:

- Range-of-motion exercises help maintain normal joint movement and relieve stiffness thus helping to maintain or increase flexibility.
- Strengthening exercises help keep or increase muscle strength. Strong muscles help support and protect joints. Building up abdominal muscle strength as well as muscles in the lower back can considerably help in reducing low back pain and instability.
- Aerobic or endurance exercises improve cardiovascular fitness, help control weight, and improve overall function. Some studies show that aerobic exercise can reduce inflammation in some joints.

Getting Going:

- First, discuss exercise plans with your doctor.
- For the 4 weeks before starting your exercise, note down in a diary a broad outline of the pattern and level of severity of your symptoms of pain/spasms etc. This helps to establish the effects of weather, time of day, stressful events, medication timing etc. on your symptoms, which can then make it easier to see if exercise is making matters better or worse.
- Start with supervision from a physiotherapist
- Choose an appropriate time of day when you are at your best: and always stick to that time. (this helps to ascertain whether any increase in symptoms is related to the exercise or not)
- Consider taking medication/using other methods to reduce pain whilst exercising: e.g Actiq lozenge (Fentanyl: related to morphine: lasts 2-3 hours, onset of pain relief within a few minutes) ; baclofen or other muscle relaxant to alleviate muscle spasm/stiffness.
- Apply heat to sore joints (many people with arthritis start their exercise program this way so this could be helpful).
- Stretch and warm up with range-of-motion exercises. These exercise joints through their natural range of movement, or as much as pain/stiffness will allow.
- Start strengthening exercises slowly with small weights.
- Gradually increase by adding 1 or 2 pound weights.
- Use cold packs after exercising (again, this is done by many people with arthritis so may be useful).
- Add aerobic exercise.
- Keep a regular diary of the level of pain/other symptoms as before in order to assess the benefit of exercise.
- Only consider recreational exercise after doing range-of-motion, strengthening, and aerobic exercise, because you are less likely to damage yourself or trigger a flare up.
- Ease off if you have a sustained increase in pain for over an hour after stopping exercising or within a couple of days (there may be a delay in the reaction, and some people do not suffer from increased pain/muscle spasms straight away).
- Choose the exercise you enjoy most and make it a regular part of day to day life. (you could try involving your partner or family or friends to make it more fun).

SUGGESTED RECREATIONAL ACTIVITIES:

Swimming: excellent, but remember to choose a warm pool; often the kiddies pool at the local baths is a lot warmer than the big pool.

For those who are more restricted, hydrotherapy may be useful.

Walking: not always easy if your feet are playing up: but get some comfy footwear and try to gradually increase your walking distance (maybe a few yards a week).

Recumbent exercise bike: a lying down position makes it easier and takes the pressure of the base of the spine. Some have various difficulty settings for different programs and may also have an isokinetic mode, which allows you to change resistance for strength training and to pedal backward.

Steps: you don't need a machine, the stairs at home are just as good. This is a good exercise for helping to stave off osteoporosis, which is more likely in immobile people.

Floor exercises: a physio should be able to suggest suitable ones.

Pilates: very 'in' at the moment.

Qi Gong : Oriental exercise which is very gentle.

MEASURES TO TAKE THE STING OUT OF IT:

- Moist heat :warm towels, hot packs, a bath, or a shower can be used at home for 15 to 20

minutes three times a day

- Physiotherapist may give short waves, microwaves, and ultrasound to deliver deep heat to non-inflamed areas. Deep heat is not recommended for patients with acutely inflamed joints.
- Cold compress: a bag of crushed ice or frozen peas wrapped in a towel helps to stop pain and reduce swelling; only use for 10 to 15 minutes at a time. (don't use on hands/feet if you have Raynaud's phenomenon).
- Topical preparations such as Capsaicin cream; helps to reduce neuropathic pain.
- Spa bath (jacuzzi)
- Massage especially with lavender oil (a muscle relaxant)
- TENS (transcutaneous electrical nerve stimulation)
- Relaxation therapy also helps reduce pain.
- Acupuncture is a traditional Chinese method of pain relief; the needles are believed to stimulate deep sensory nerves that tell the brain to release natural painkillers (endorphins). Acupressure is similar to acupuncture, but pressure is applied to the acupuncture sites instead of using needles.

HOW OFTEN?

Range-of-motion exercises daily (at least every other day).

Strengthening exercises also can be done daily; should be done at least every other day unless you have severe pain.

Endurance exercises: 20 to 30 minutes three times a week unless you have severe pain.

Recreational exercise: as often as is tolerable.

WARNING SIGNS:

If any of the following occur, you should discontinue your exercise programme and consult your doctor:

- Unusual or persistent fatigue
- Increased weakness
- Decreased range of motion
- Joint swelling
- Continuing pain (pain that lasts more than 1 hour after exercising)

EXERCISE WITHOUT THE EFFORT?

The machines which 'tone' various bodily parts will only do so if the muscles are able to work properly; for instance, in my case, the muscles of my lower abdomen (aka my 'belly') are split after my 3 pregnancies. No amount of Slendertoning is going to reunite the split parts.

Whilst we would all like to think we could go on some machine that would do our running for us (or at least, for our muscles) the truth is, that this sort of equipment isn't available to us as yet.

For a few people who have marked muscle weakness, medical versions of this sort of machine may be used to stimulate the muscles to improve the power. However, for the majority of us, we have to do it for ourselves.

SO HERE'S THE 'SKINNY':

1. Fat is NOT a feminist issue! It is no discriminator, men and women alike are prone to its attack. (and women are the worst culprits for being derogatory about other women who are overweight!)
2. There are no 'short cuts' to losing weight
3. We need to embark upon a change in lifestyle.
4. This will impact not only on our weight (hopefully) but also more generally on our physical (and possibly emotional) wellbeing.
5. Some of us may try everything within our power, but not lose weight. (for those people: see my message below)

FAT CHANCE!

Members who have seen me at AGMs or on video will wonder whether I am merely being patronising as they have seen the slim version.

I haven't ever got to Sumo wrestler proportions, but I have had times in my life when I have been considerably overweight.

I have 2 close friends, who have had to lose weight for medical conditions and have had considerable difficulty.

Since stopping smoking over a year ago, and starting amitriptyline, I put on about a stone and a half. Now that I am on morphine, I find I do crave sweet stuff a lot.

In the last month, I have been on gabapentin for nerve pain. The good news is that it is starting to be effective, the not so good news is that I've gone up a clothes size or more within that time. As I am on increasing doses, I can't see it being likely I will start losing weight: indeed, I could be faced with further increase.

So I am not speaking from the rarified privilege of the former 'fattie' or the 'never been fat' person.

There's no doubt that being overweight is upsetting. A few evenings ago, I went through some of my clothes and found that items that I'd bought to cater for the previous few months' weight gain (some purchased only a few weeks ago and fitting up to a fortnight ago) were nowhere near fitting. I must confess, I was very upset.

But...and this is a big but (not, as the American's would say, a big Butt!) I have realised that there are 2 fundamental differences between now and when I was overweight in my early 20s:

First, to a large extent (pardon the pun), my weight gain is not my 'fault', it is out of my control, being medication-induced. That means that once friends and family are aware of that, I don't

feel that I am being judged harshly. (the rest of the world's opinion doesn't really matter much)

Secondly, I have more important things to concern myself with, worry about or be upset by, and this puts my weight into perspective.

So, to sum up, we do need to pay some heed to these 'weighty matters' but they should always be kept in perspective.

I guess we can chalk up being overweight and 'losing our figures' to arachnoiditis, another aspect of a condition which can take over our bodies, but never our spirits.

Sarah Smith (nee Andreae-Jones) MB BS

Patron of the ASG

July 2001.

(The doc is back to being slim and petite again - perhaps she should tell us how. Ed)