



# NEWSLETTER

ISSUE 2 - September - December 2020



## INOCA WEBSITE

Our new website is proving to be very popular indeed. If you haven't visited it yet, please do! The INOCA International website has superb video presentations and information from medical professionals and world leading experts in INOCA conditions. Information includes a dedicated Patient Information page with a freely downloadable pdf sharing the experiences of 130 INOCA patients from around the world!

### Juggling Nitro Medication

The effectiveness of GTN can only be seen when the patient and those who care for them:

- Spray:** This effective medication can be used in minutes.
- Patches:** Patches are effective and can be worn in minutes.
- Sublingual:** Sublingual GTN tablets are effective in 2-3 minutes and can be used up to 8 weeks.

Don't be afraid to prescribe all three forms of GTN. GTN comes in a different form, each with its own advantages. GTN comes in an immediate-release form, which is used in minutes. GTN comes in a different form, each with its own advantages. GTN comes in an immediate-release form, which is used in minutes. GTN comes in a different form, each with its own advantages.

## NEW EDITOR IN CHIEF



We are delighted to congratulate our INOCA Medical Advisory Board member Professor Filippo Crea as the new Editor In Chief of the European Heart Journal. A great handover from our INOCA Medical Advisory Board member Professor Thomas Lüscher who was Editor in Chief for the previous 11 years!

The website can be seen at [www.INOCAInternational.com](http://www.INOCAInternational.com)

For our Facebook Information Page please search for **INOCA INTERNATIONAL**

We also have a Twitter page [@INOCAInternati1](https://twitter.com/INOCAInternati1)

## MEETING OF MINDS



The Meeting of Minds is extremely important to us all but the health and well-being of everyone involved must always take priority. As a sensible precaution INOCA International will not be finalising the date for the next Meeting until the Coronavirus situation is under control. We are continuing with plans behind the scenes and are looking forward to sharing these with you all when the time is right. If you are interested in becoming a sponsor of the 2021 INOCA International Meeting of Minds, we would love to hear from you!

## DID YOU KNOW...

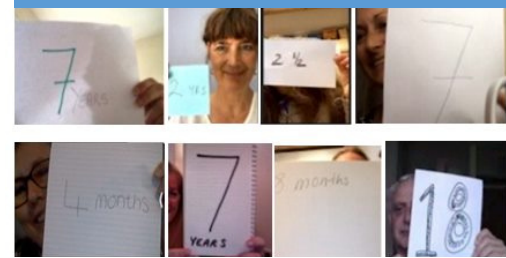
That only 10% of the coronary tree can be seen on a standard angiogram? Did you also know that over 70% of the blood flow to the heart muscle is regulated by the microvasculature? A clear angiogram doesn't always mean you do not have heart disease - the problem may be in the microvessels!

## NEW PUBLICATIONS

**EAPCI CONSENSUS DOCUMENT**  
and  
**THE ASSESSMENT OF VASCULAR DYSFUNCTION IN INOCA**

Links to the documents can be found on the Articles page of the INOCA International website [www.INOCAInternational.com](http://www.INOCAInternational.com) (scan the QR code above to visit the INOCA International website)

## CAFE CONVERSATIONS



It was great to welcome members to the first ever INOCA Cafe Conversation. The topic was 'Journey to Diagnosis' and caused a lively discussion. Time to initial diagnosis for attendees ranged from 4 months to 18 years! The feedback has been very positive and we are already looking forward to the next one! If you would like to join our Cafe conversations please contact us via the INOCA website.

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## Living With A Chronic Condition

Dr Ailsa Care, GP



As a practicing GP for over 25 years, I have cared for many patients living with a chronic condition. Prescribed medication is obviously very important and can often help to treat the condition and manage symptoms, but there are other things too which can also sometimes be of help.

**Low vitamin D** - This is such a common finding for people living in the UK especially if we have a darker skin, avoid sunlight exposure or spend most of our time indoors. Consider asking your GP to test your vitamin D level and treat accordingly. Public Health England recommends that everyone in the UK should take 1000iu vitamin D from September through to April to prevent a deficiency.

**B12 deficiency** - This can affect every body system and be responsible for multiple symptoms and is a contributing factor to many chronic illnesses. You can explore this by completing a symptom checker on [www.b12d.org](http://www.b12d.org). Again it is worth asking your GP for a B12 test as replacement B12 can make a huge difference for those with a deficiency.

**Pacing**. For those with a chronic illness it is very easy to push ourselves on a 'good' day resulting in an increase in symptoms. This is where pacing is so important. A useful tip is to consider all your regular activities and think about how much of your energy each requires, maybe give it a number of units. You can then work out how many units you have in a day before you run out of energy. Try and plan your day and not overuse your units to prevent exacerbations.

**Movement** - This doesn't need to be strenuous exercise just moving around regularly is enough. Simple things you can try are to stand on one leg to improve your balance and core strength whilst brushing your teeth or waiting for the kettle to boil (you may want to have the back of a chair nearby in case you need to hold on to start with) or perhaps try

stepping up and down on the bottom step of your stairs and see how many steps you can do in 30 seconds, walking or gardening.

**Stress**. Modern life is inherently stressful but often not big, life threatening stresses but the smaller 'micro' stresses. If we are constantly stressed our bodies are not having the chance to digest our food, tidy up, get rid of the rubbish and repair. These are the essential functions which take place when we rest and relax and this should be our default state rather than 'fight or flight'. Constant stress has been shown to increase inflammation which is associated with every chronic disease e.g. heart attacks, stroke diabetes, dementia, depression.



**Relaxation** activates the balancing part of our systems which helps us to digest our food better, sleep better and start repair processes. If your body is constantly in fight or flight mode then your immune system is activated resulting in inflammation. Too much inflammation is associated with every chronic disease e.g. heart attacks, stroke, diabetes, dementia, depression. So learning to relax will help switch off this inflammation.



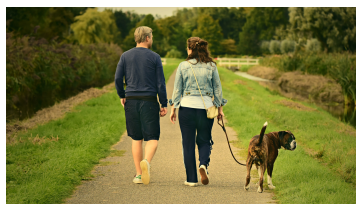


**FEATURED ARTICLE - continued**

**Nutrition** – What you eat makes a huge difference to your health. I like to think of food as medicine. It should provide us with the raw materials we need to be able to heal and repair as well as providing energy and nutrients for essential processes. Try as much as possible to eat real food with plenty of fruit and vegetables of different colours. This provides us with lots of lovely fibre, which our healthy gut bacteria love and phytonutrients, which have multiple benefits in supporting our immune system, heart health, hormone health, cancer prevention etc.



**Community** – It is so important to have people 'in your corner' who support you. This may be family, friends or people you attend a class with or even the INOCA Cafe! You are not alone and sharing your experiences with like minded people is so valuable for anyone with a chronic health condition.

**Five things to try which you might find of help**

**1. "Me-time" every day.** Just 15 minutes is all you need. Examples of me-time include: taking a bath, going for a walk, reading, sing or dance to your favourite music, gardening, cooking, painting, colouring, yoga, tai chi.

**2. Reduce your reliance on e-devices**

Did you know an average person checks their phone around 200 times per day and total screen time can amount to over 3 hours daily? Try these simple steps to reduce your use. Switch off push notifications you don't need. Unsubscribe from redundant email lists. Set emails to refresh manually. Don't bring devices to the dinner table. Switch off devices 60-90mins before bed. Have some e device free periods during the day. Aim to have 1 day per week e-device free - how amazing would that be!

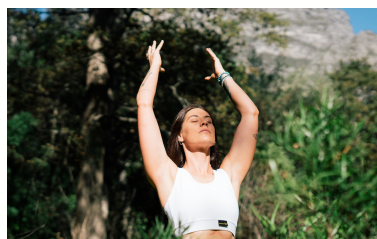
**3. Keep a gratitude journal**

Each night before you go to sleep write down all the things that have gone well for you that day and the things you are grateful for – they can be really small things or more important. Studies have shown that people who do this for a week see lower levels of depression and increased satisfaction with life.

**4. Practice stillness daily.**

This should be for a minimum of 5 minutes daily. Consider having a special sanctuary in your home where you can practice in comfort, undisturbed. Examples of stillness practice might be:

Guided meditation with a phone app like Calm or Headspace. Deep breathing – in for 3, hold for 4, out for 5. Yoga breathing e.g. breathing in through left nostril for 4, hold for 4, breath out through right nostril. Five minutes of mindful colouring. Sitting in silence aware of all your senses – feeling your feet on the floor, legs on the chair, sounds in and outside the room, any smells etc. Listening to music mindfully – with headphones on, eyes closed, fully focused.

**5. Reclaim your dining table**

Eat one meal per day at the table, with company if possible, without your e-devices. You are more likely to be relaxed and to digest your food properly



## FURTHER THOUGHTS ON PACING from INOCA patients

Pacing is not necessarily about decreasing the intensity of an exercise, doing less activity, or being unproductive. Pacing can provide structure to the activity and can minimize pain whilst maximizing productivity overall. It is important to try to find a good balance between work and rest so our bodies can keep up with the demands when pain, illness and injury are brought into the equation. The body may need more rest to heal but our jobs and daily activities don't go away. In many people with a chronic health condition there can be a pattern of activity that tries to meet what needs doing, as well as having time to rest. This is often referred to as 'Boom and Bust'.

Boom is when you may be having a 'good' day so you try to catch up on all the activities that need doing. Bust is needing to take long periods of rest to recuperate from the overexertion and the possible trigger to pain/angina symptoms.

Needing to take long periods of rest is a very natural response but sadly this can also come at a cost, as muscles can start to get weaker and we can generally become less fit. Over a long period of time we can also become de-conditioned.



It can help to choose the most important tasks to be done (prioritise) and then only do those in a paced way. 'Pacing Down' can be the hardest part where you need to break your activities into smaller chunks. For example you may find you need to;

Plan activities in advance; breaking them into chunks, asking yourself what does each stage involve? Take regular rest breaks, these could include; stretching, relaxation and changing position.

Prioritise; do you need to do it? When does it need to be done? Could someone else help?

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To achieve Pacing Down and to avoid the Boom & Bust the 3D's are a simple way to remember what might help:

**Ditch it**- do you really need to do that task?

**Delegate it** - can someone else do the task for you?

**Do it** - if it really needs to be done, do it in a paced way.

Pacing can be one of the most difficult things to do. It can be frustrating on a 'good' day to try and hold back, but if pacing is followed it can sometimes have great benefits for our health and wellbeing.

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We also asked INOCA patients if there was anything else they thought might be of help for others living with INOCA. This is a summary of what they said -

- Allow yourself to mourn for the life you have lost.
- Accept you may not be able to have that same life.
- Identify your triggers to try to avoid acute episodes.
- Enjoy the simple things in life & live in the moment.
- Learn to say no and expect plans might change.
- Getting great care can make all the difference.
- Share your experiences with others.

Whether you are a patient, a medical professional, a family member or a friend - Living with a chronic condition can be devastating to health and also to future hopes and dreams. You may not feel that you are able to help at times. In those instances, please just be kind. Being kind can help to give hope and can make life and all its new unwelcome challenges, seem so much more achievable.



*'Having had to retire early on the grounds of ill-health  
Leading me to find new ways to develop myself  
One of the main things I now like to do  
Is write poetry, as I'm now showing you!'*

Stephen Miller 2020





## 'ASK THE DOCTOR'

Our sincere thanks to

**Dr Ailsa Care GP**

for hosting our regular 'Ask The Doctor' section

## FREE SYMPTOM TRACKER

INOCA INTERNATIONAL – DAILY ANGINA/SYMPTOMS TRACKER – ABC FORM

Date/Time Location	What happened again before the angina episode (Antecedent)	Description of symptoms (Manifest)	Duration/Symptoms Lasting	What helped ease the symptoms (Consequence)	Observations BP/HR etc
A - at rest 1 during the day, 2 wakes from sleep	A - chest pain, central unless stated 1 sharp stabbing pain, 2 pressure, 3 achy/heaving, 4 burning, 5 other - please specify	A - less than 1 minute	A - deep breaths		
B - post exertion 1 walking, 2 showering, 3 drying hair, 4 housework, 5 other - please specify	B - across shoulder blades back pain 1 cramping, 2 sharp stabbing pain, 3 other - please specify	B - lasting 1-30 minutes	B - rest		
C - Environmental pollutants 1 noise, 2 lighting, 3 crowded environment, 4 other - please specify	C - jaw pain, left side unless stated 1 ache, 2 pins and needles, 3 sharp stabbing pain, 4 other - please specify	C - 30-60 minutes	C - using GTN spray/tablet 1 one dose, 2 three doses, 3 three doses, 4 other - please specify		
D - emotional stressor/situation	D - arm pain, left side unless stated 1 deep ache top of arm, 2 deep ache elbow, 3 other - please specify	D - 30+ minutes	D - medication		
E - change in weather conditions 1 hot to cold, 2 cold to hot, 3 stormy, 4 other - please specify	E - exhaustion 1 cannot keep eyes open - have to sleep, 2 cannot perform usual functions, 3 other - please specify	E - unknown	E - medical consultation - please specify		
F - other 0 - unknown	F - other 1 - other - please specify		F - 111 rung		
			G - GP contacted		
			H - A&E visit		
			I - ambulance called		
			J - other - please specify		
22.06.20 14.30	F - zoom meeting at work	CL, 44	0	A, CL, CL	90/50 92%

### 1a What are the main symptoms of Vitamin D deficiency?

The common symptoms I find in general practice are musculoskeletal pains. But vitamin D is involved in so many other body processes, not just bone and muscle health. It has roles in the immune system, in blood sugar regulation, cancer prevention, it helps to reduce inflammation and is important in mental illness too. It is a factor in the development of osteoporosis and rickets in children if it is persistently very low.

### 1b What are the main symptoms of B12 Vitamin deficiency?

Vitamin D deficiency can affect every body system potentially. It is more common in vegetarians and vegans as it is mostly available from animal sources but also common in people taking certain medications which reduce its absorption from the stomach and anyone with malabsorption disorders such as coeliac disease or after gastric bypass surgery. I see patients presenting with all sorts of neurological symptoms like tingling, headaches, tremor, memory problems, dizziness, tinnitus, anxiety, depression and fatigue is very common.

### 2. Is it ok to have Vitamin D levels just above the lower limit of normal?

It depends! If you are just above the lower limit of normal and it is the start of the winter then I would be looking to optimise your level by taking a supplement as it is likely to drop further without strong sunlight exposure. If it is at the start of the summer months or you are expecting to go on a sunshine holiday and you will be spending lots of time outside then you will probably make enough vitamin D to optimise your levels. If for whatever reason you spend most of your time indoors or your skin is sensitive to the sun then you would be wise to continue a supplement of vitamin D all year round.

***Don't forget that vitamin D is fat soluble and best taken with a meal containing some fat so it will be better absorbed.***

### 3. Have you seen an increase in patients presenting with CAS/CMVD as a result of increased awareness?

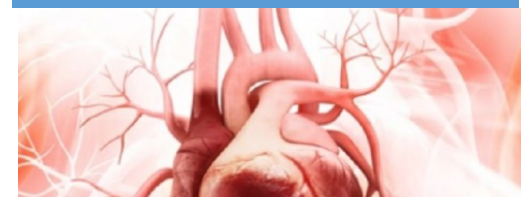
I'm not sure that I have seen an increase in patients presenting with CAS/CMVD but we are in rather unusual times! Certainly before lockdown I had queried the diagnosis in several of my patients and sent them off to cardiology for investigation. I think it is more my increased awareness that has changed rather than the number of patients presenting.

The INOCA International Symptom Tracker is available to download free of charge from the Patient Information page on our website. Designed by one of our INOCA patients it is a great tool for patients and medical professionals!

## CHRISTMAS NEWSLETTER

We are planning a special December Issue of the INOCA Newsletter to mark the end of a very difficult year for many and to help us all to look forward to 2021 with enthusiasm and hope. Make sure you don't miss our Christmas issue!

## DONATIONS



Funds raised via GoFundMe go towards covering the costs of the Meeting of Minds. They also cover other costs such as website hosting. No member of the team is paid. If you feel that INOCA International has helped you in any way, can we please ask you to consider making a small donation to help us continue our efforts to raise awareness and further education in INOCA conditions?

**"THANK YOU"**

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