

Revealing Chronic Pain:

Art Gene Exhibits Blogger Ciara Chapman's *My Chronic Pain Diary*, and Hosts an Open Conversation on Facebook.

By Ruth Pringle

In 2017 I was guest curator for **Art Gene's** *Digital Gene Pool*: a curated online exhibition space showcasing innovative digital art. In keeping with Art Gene's strong research remit, *Digital Gene Pool* is also an ever-growing archive intending to capture the inherent potential of digital art forms. What struck me on seeing Ciara Chapman's application with her blog *My Chronic Pain Diary*, was the sweet charm of her work coupled to the insidious nature of her illness. Technically her blog was not testing digital boundaries in the sense we had been looking for, but I was impressed by this artist who shared personal information online about losing control over her lifestyle, body and relationships so frankly; creating visual metaphors that help people without such a medical condition understand a sufferer's alternative world. Part enraged cries, part exultation, her blog captures daily details of the defeats and victories in her private battle to not let her illness own her. At Art Gene, we debated and agreed that the communicative potential of her blog could and should be explored. We invited Ciara to exhibit with us as a blogger - for five weeks Ciara would share her weekly images on our site, additionally sharing the backstory of both her inspiration and artistic processes.

Here at Art Gene (Barrow-in-Furness, UK), we are preparing an upcoming project called *Linking our Landscapes and Communities*. Designed and managed by *The Coastal Communities Team* (an association of stakeholders of the Cumbrian coastline, initiated and headed by Maddi Nicholson, co-founder Director of Art Gene) this project will unite artists and a range of experts in team research to devise and produce long-term and progressive ways to reverse the entrenched and shocking health inequality that is endemic in our area by (re)engaging the local public with the magnificent landscapes and nature reserves of its locality. As with all our project work, outreach and public engagement is both our starting point and process and we continually test and assess ways to reach and engage new audiences and participants.

As Ciara began writing about her visual blog posts for us, it was clear that she also has an appealing skill for spoken communication on health and art issues, so we invited Ciara to take part in a series of **Facebook** conversations on the Art Gene page, where I would (very informally) interview Ciara about her week's output - but which, crucially, were open to anyone to contribute. Were these conversations successful, Art Gene would gain a new tool to reach and engage people for *Linking our Landscapes and Communities*. Either way, we were probing the digital potential of Ciara's blogging work, which for us, strengthened its place in the Digital Gene Pool Archive and Exhibition Series.

What follows is the majority of our weekly chats. Week two is quite short as Ciara had a medical appointment, but we deliberately left it hanging open in the hope that someone else would jump in. By week three, other artists with Chronic Pain were waiting for us to begin our chat, and also began posting images of their own artwork and discussing it in relation to their own experiences - which was a very welcome

and unexpected turn for our Facebook threads. These conversations overlap a bit due to the nature of threads on Facebook posts (where two people can reply simultaneously), but I decided against editing down the content - including correcting typos. You can of course find the full conversations with all the images at <https://www.facebook.com/ArtGeneLtd/>.

24 October, 2017

**Art Gene** Hi [Ciara Chapman](#), how are you today?

**Ciara Chapman** Be very careful asking me a question like that- I might start moaning 🤔😓. I'm good thanks! Sketching this morning- no nicer way to start the day.

**Art Gene** Glad to hear it! Have you got an idea that you are working on? Or just having some fun with pencils?

**Ciara Chapman** **Art Gene** it's flu season and we're all doing our best to escape unharmed so I'm focusing on that at the moment. Want to see some sketches?

**Art Gene** Definitely!

[images posted]

**Art Gene** Haha, the image of you and your husband is like a scene from a zombie film. Does flu season make you that paranoid about seeing people or going into society?

**Ciara Chapman** **Art Gene** it really does!!! I currently have a pathetically weak immune system because I'm inside my house so much so I dread flu season, I

become a germ magnet 😊

**Art Gene** It's a horrible one. The people you love can unwittingly make you unwell. I'm sure it makes everyone feel cautious, and no one wants that barrier to physical contact or friendship.

**Ciara Chapman** **Art Gene** very very true! I'd never stop people from calling to see me or let it stop me from leaving the house because I think you could easily open yourself up to a much more difficult problem in doing that but I won't lie- it definitely crosses my mind when I go to the doctor and sit in the waiting room!

**Art Gene** Ha, I think dr.'s waiting rooms do that to most of us to some extent. Seeing my daughter's friends with runny noses running towards her does it for me. But the implications are different for you, right? How bad is flu for you?

**Ciara Chapman** **Art Gene** it's very difficult in my situation because if I get so much as a cold it makes my nerve pain so much worse. If it's a tummy bug then that means the medication I depend on won't work properly because I can't keep it down but the worst part is that it's never ending. I got flu in July and it seemed to last for about two months. That meant no physio which caused pain elevation and muscle degeneration. Mentally If you're feeling low, it also means pain becomes more intense, it's very hard to not feel low when you're under the weather especially when it lasts so long. Flu is soooooo difficult for anyone who is isolated as a result of their medical conditions.

**Art Gene** I used to work for one of the top medical advisers France as an English teacher. It was a few years ago when there was the H1N1 flu scare and the government urged everyone to get vaccinated against it, expecting a huge outbreak. He was one of the first in the queue to get a jab, and I asked him if it was because he was a frontline medical worker, and he replied 'no, it's because I am a

citizen'.

**Ciara Chapman Art Gene** I'm never sure whether or not to get the jab, any time I've gotten it I got quite a bad flu immediately followed by about 3 different instances of flu after that. Are you a fan?

**Art Gene** I'm lone parenting a toddler. I'm not a fan, but if I get ill then we are both in a lot of trouble, so I'll get the jab. But I know a few people who say the same. People with imperfect immune systems seem to suffer from after effects of the jab.

**Ciara Chapman Art Gene** little ones seem to pick everything up in nursery don't they? You're spot on about taking whatever measures you can to avoid it reaching you. Single parents are super heroes but only Superman can avoid the flu.

**Art Gene** Ha, that sounds a bit more glamorous than it sometimes (often) feels. There's a bit of a hint of a caption in there too.. could this be the start of a drawing?

**Ciara Chapman Art Gene** great idea!

**Art Gene** Will your drawing help to explain to people around you? Or are you mostly making for an unknown audience?

**Ciara Chapman Art Gene** initially I thought it would help people close to me understand the day to day of my situation but as it happens they can't always bring themselves to look at my diary I think it's painful for them which is something I hadn't considered. Now I'm making them for me and posting them for an audience of people who are experiencing different types of pain (mental/physical/emotional) and their loved ones who are trying to understand and connect with them.

**Art Gene** It's terribly sad that your work hurts your family to see. I guess they can see your stick or crutches and hear pain in your voice too, even if it may be a bit easier for them to pretend not to. The work is less avoidable somehow. It puts the viewer straight into your own situation for a moment.

**Art Gene** It's nearly 12. Time to go and pick up my girl... It was brilliant chatting to you today Ciara, I hope you enjoyed it too. Speak soon! And I'd like to remind everyone that they can join in if they like. If you want to comment on anything in the thread, just do so. If you want to ask something different, just post a comment in the comment box under Ciara's artwork above. She's happy to answer your questions.

31 October, 2017

**Art Gene** Morning **Ciara Chapman**! What have you been working on?

**Ciara Chapman** Morning! I'm still working on the illustration for Flu season that I showed you last week. But I've also just finished this diary entry- *number 90: November is nerve pain awareness month....*

[image posted]

**Art Gene** Hi! Good to hear from you. *November is Pain Awareness Month* has more than a touch of public health information campaign. Is it a commission - or are you hoping it's going to fly around the internet by itself?

**Ciara Chapman** I can see what you mean. That wasn't really the intention it was more a means of making it a much more general illustration than anything. I use a huge amount of symbolism in my usual entries but I wanted this to apply to anyone.

I did a similar entry in September for chronic pain awareness month and I'm continuing the theme. I'm also very fond of Chronic Pain Ireland- they've helped me a lot in such an uncertain time in my life so I'd like them to be able to use the illustration if they'd like 😊

**Ciara Chapman** This was September's post  
[image posted]

**Art Gene** Well I hope they do use it. I think your work has such charm that it has the power to reach a lot of people. I can see it as a leaflet - as well as getting shared around Facebook and such. I thought it was interesting what you said about your work, *Poor Dave, I've Learned to Snore*. About how you were wary of speaking for other people and telling their story.

**Art Gene** It is a delicate line to talk so openly about your own life without making parts of another person's life public too.

**Ciara Chapman** **Art Gene** very true! I always check with Dave if I'm including him in an illustration, I give him final say too before posting it- I'd never want him to feel like I was taking for granted that he would want to be included.

07 November 2017

[images posted]

**Art Gene** Good morning **Ciara Chapman**, this image popped into my inbox overnight. Can you tell me a little about it?

**Gwen Kennedy** Morning **Ciara Chapman** is this the conversation piece?

**Ciara Chapman** It is Gwen, thanks for joining! I shared this illustration with Ruth from ArtGene yesterday ahead of our chat today. I had a break from physio recently because of bad health and have started what I think of as another cycle of it again. As a person with chronic pain who is also very creative, do you find your creativity pulls you through Gwen? Btw please share your work.

**Gwen Kennedy** ♥ this piece can see the flux of pain cycle in it...

**Ciara Chapman** Thanks Gwen! Both pain and physio feel like they go round and round and round in never ending loops. Composition wise, I liked the idea of containing the movement in a closed loop, the bright pink in the middle represents the gym matts.

**Gwen Kennedy** Ive an excercise physio excercise matt where many would have a rug.. and yes I think we all see different things in art based on our life experiences my piece to me is about Chronic pain but could be to do with invisible chronic illness or addication.

**Art Gene** HI Gwen

**Art Gene** thanks for joining us! You mention the flux of a pain cycle, which makes sense now I read it, but I wouldn't have seen it (probably as as it is not within my own experience). Do you think as a pain sufferer yourself (I am guessing) you often see more in an image by Ciara than I would? Do you understand all her symbolism?

**Gwen Kennedy** This represents 'The face of Chronic pain ', and without a shaddow of a doubt. I woke with this image in my head on a Monday morning after aChronic pain Ireland workshop. My emotion also comes through as it represents pain thats invisable/and the types of pain plus the many meds I take just to get out the door!

[images posted by Gwen]

**Gwen Kennedy** I can see the pain cycle flux in your piece [Ciara](#)

**Ciara Chapman** [Gwen Kennedy](#) love that piece Gwen, can you explain the thought behind it?

**Ciara Chapman** [Gwen Kennedy](#) it does look like the face of pain. One side is what you present to the world, the other is what's really going on underneath.

**Art Gene** Gwen is your artwork mostly autobiographical too? Can it help those around you understand more about your illness?

**Gwen Kennedy** Yes I did this piece at a mental health art group I've started going to lately and many people there some with out chronic pain with other issues found it powerful. I write about pieces when I wake with an image and then try to flesh out in drawing /painting...

**Ciara Chapman** [Gwen Kennedy](#) how long did this one take?

**Gwen Kennedy** Roughly 8-9 hours including writing about and an initial presketch tablets took the longest because I tried to keep to colours of real tablets admittedly not all for chronic pain ... loved using lidocaine gel syringe for nose.... 😊

**Ciara Chapman** [Gwen Kennedy](#) it's very clever! Do you find it difficult to know when to stop- overworking is such a danger isn't it!

**Gwen Kennedy** Yes I do have asked a few others for advice on this put it in a portfolio folder for a week at this point to stop myself for a week then fresh eyes one last time donating it to Chronic Pain Ireland for 25th anniversary raffle but may print a few photos of it for myself also proud of this one this week I've been sketching 'Baggage we've all got it!!'

**Gwen Kennedy** Only fell back into art and creativity when I ended up in hospital!!

**Art Gene** How does it help you deal with what you are experiencing?

**Gwen Kennedy** Keeps me grounded I turned my room in hospital that time into a mini Gallery!!I've also started an art &creativity facebook group for people with chronic pain Cork based but with global membership.

**Corina Duyn** Interesting Gwen,

**Gwen Kennedy** I've started using the library as a sketching place in last few weeks

**Frances Heneghan** I find this piece interesting, [Ciara](#). To me, it's a symbol of the wires of pain forever weaving through time. What did you intend to portray?

**Ciara Chapman** That's very interesting Frances, you always have such a unique point of view! I sort of consider the wire to be my physiotherapists, they pull and push in so many (necessary) ways that I sometimes feel like a puppet on a string.

**Frances Heneghan** I tend to feel physiotherapists control my every movement, so yes, puppet on a string! I changed over to yoga as a motion therapy, and feel more in control as a result.

**Ciara Chapman** [Frances Heneghan](#) I'm looking forward so much to be able to do a yoga or Pilates class once a week instead of physio! Writing anything interesting recently Frances?

**Art Gene** Hi Frances, thanks for joining in. Its good to hear what you say. Do you follow Ciara's blog? And does the way she describes her experiences of chronic pain help you deal with your own in any way?

**Frances Heneghan** Yes, I've been following Ciara's blog/pain diary for some time. I love her pictorial representations, they link to my own experiences with pain and

life. They are a mirror for me. I really admire Ciara's absolute consistency, I'm not consistent in writing and I'd love to ask her how she controls her daily output?

**Ciara Chapman** **Frances Heneghan** I spend most of my day sitting in one chair in my sitting room so I have a teeny tiny studio set up around me. On days where my pain is lower I draw an idea that would pop into my head when my pain is high and if I'm having a bad back and leg day I use photoshop because it forces me to sit in a specific position that works on those days. One thing I've learned through my diary is never to force an idea. They come when they come. Yesterday I just felt like sitting around drawing bunnies for the day so that's what I did.

[Image posted]

**Gwen Kennedy** Gotta love Opie great campion.

**Frances Heneghan** I feel embarrassed to admit I don't have anything like your consistency, **Ciara!** I plan what to do but often have to leave it for following days. I start with a good run and bang! pain calls a halt and it's back to the medical train again. I have a dictaphone, which I use for writing, but it's just not the same as pen and paper.

**Ciara Chapman** **Frances Heneghan** quality and quantity aren't the same thing though. I've read some of your writing and it's wonderful- whatever you're doing is working!

**Frances Heneghan** Exactly what I've been advised, **Ciara!**

**Ciara Chapman** **Gwen Kennedy** he is- he's in a bad mood this morning but I'll love him anyway 😊😊 a companion makes a world of difference when you're isolated from the rest of the world.

**Frances Heneghan** **Ciara**, have you decided where your images in your chronic pain diary are heading? I would think a book (or series). I understand you have an exhibition running at the moment, do you feel you're baring your soul?

**Gwen Kennedy** Calender prehaps **Ciara** would happily have one by you on my wall!!

**Frances Heneghan** Good idea, **Gwen!**

**Ciara Chapman** **Frances Heneghan** I'd love love love to do a book but they're very expensive to make so I've applied for funding- fingers crossed!

**Ciara Chapman** **Gwen Kennedy** great idea Gwen!

**Corina Duyn** **Ciara Chapman** I agree with your thought, that through your diary you learned not to force an idea. Well put.

**Art Gene** Have you thought about crowd funding it - through Kickstarter or some such?

**Gwen Kennedy** Good idea not sure how that works...

**Gwen Kennedy** Was thinking of approaching a few local businesses see if I can get something out of them ...I dont really have a great head for figures or how to go about other than I donate button on Facebook....

**Frances Heneghan** **Gwen**, Google Kickstarter, you'll find out how to set it up and get financial backing from those who would like a copy of book (or any product) that creator displays.

**Gwen Kennedy** Will take a look and go back to group to discuss and have a chat with a few potential venues ...

**Art Gene** Kickstarter essentially links people who want to support the arts with projects. You make a page advertising your project and people chose to invest - normally for rewards such as a final artwork or edition of prints. Its a way for people to collect art and support artists (of all kind). The thing to remember is that you need to reach your target amount before you receive any funding. It is an all or nothing thing - which protects the investors.

**Frances Heneghan** Art Gene Much better explanation than mine!

**Gwen Kennedy** Yes so you need to know what your offering pre setting up kickstarter ...do you need to set up seperate account to draw down kickstarted funds?

**Gwen Kennedy** You ok **Ciara** I dont want to take over your conversation time!!

**Matt Sanderson** Aside from the absence of a skirt in my wardrobe 😊😄, that picture just about captures perfectly my ongoing Chronic Widespread Pain condition, and the challenges of day to day life and academic studies (as well of course as being a keen supporter of Art Gene!)

**Art Gene** Hi Matt! Thanks for joining us! I know of you and your work through Art Gene (I made your page on our website), but was unaware that you also fight chronic pain. Is it something you talk openly about or do you prefer to keep it away from professional situations?

**Matt Sanderson** It's pretty apparent, when people meet me, so can't really avoid it. I had a massive injury about 9 years ago (de facto broken neck and damage to nervous system), and one of the resultant conditions is CWP.

**Art Gene** I didn't know. I'm amazed you do so much. I know you are in post grad education. The thought of studying whilst living in pain is remarkable - but I think this is what everyone is telling me today. You work out all the strategies you can to not let it stop you from being who you are. You live in Barrow-in-Furness where Art Gene is - and you work with mapping? Are you out in the landscape much?

**Art Gene** Are you able to access the local landscape - and do you have ideas about how to get it more accessible for anyone physically unable to move far? Have you got involved in the Coastal Communities project yet?

**Matt Sanderson** **Art Gene** see PM.

*(Matt and I subsequently chatted on Skype - and he told me about his involvement with Coastal Communities as Treasurer)*

**Berni Shine** That's a lovely elegant piece Ciara...like a dance ..negotiating your way through living chronic pain. It also remi d's me of puppets. .some outside force pulling our strings.. I live tour diary entries.. they are little stories I look forward to. I work a lot differently.. but find the creative process takes me away..its both exciting and difficult at times. There are so many different forms of creativity.

**Berni Shine** \*love your\*

**Art Gene** Hi Berni, thanks for joining in! Are you an artists and a pain sufferer too?

**Corina Duyn** I agree, as it hsppens my own latest creative work is based around puppets. So interesting to read your thoughts.

**Berni Shine** Hi yes both...i have chronic pain over 15 years now. I gave up art college when it started.. it took a few years to get back to creativity..but it's a tremdous outlet. I love the was ciara works. We all have different ways of expression. I also create cards ...worhout this outlet is be lost.

**Berni Shine** Forgive the typos...

**Art Gene** Of course! (typos comment) So Berni, in fact your illness took away (or postponed) your ability to create - and your college career. It's good that you can now get back into it. Do you (and everyone) find support for creative activities through Chronic Pain Ireland, or Arts Council or other bodies?

**Art Gene** Hi Corina, thanks for joining in. Please do share your work if you would like.

**Ciara Chapman** There really are Berni! When I'm stuck inside I love looking at photos of places I'd like to be, or if my leg feels like it's not working at all, I watch dancers and gymnasts. Even looking at things people make for their homes for pets- it's all so creative!

**Art Gene** I find that really inspirational Ciara - that you can get pleasure from the movement of others. (I'm not sure I would be so generous hearted in your position). Has it drawn you towards art forms (like dance) that you wouldn't have been interested in previously? Have you contact with any dancers? I know that they too push through pain barriers - and they have such great awareness of their own health and bodies. It is interesting that the two extremes of physical movement have so much in common.

**Ciara Chapman** **Art Gene** I think so too! The braces I wear are worn by sports people who put their bodies through the mill- two completely opposite reasons for wearing the same thing is incredible!

**Corina Duyn** Dance and movement. Like Ciara, I watch movies about dancers, and try to replicate part of this in my work. I think we can be free (or free-er) to move within our work than we can within our bodies.

**Art Gene** Thanks all for your contributions so far. It is eye-opening. I suppose one problem is that you are to some extent hidden away by your illness too: if you can't move out of your house, then you are not meeting so many people - missing all kinds of casual interactions that would help to make wider society aware of chronic pain. It is sort of why making art or writing is essential for you. It is not just an expressive outlet to feel better (which I'm sure it does too) - it also represents your presence in society on the days you can't physically be there.

**Art Gene** I'd like to project a dancer onto each of your homes - just to remind everyone that you are in there!

**Art Gene** What are more practical things that an arts organisation could do to help people with chronic pain? Remember we (at Art Gene) are trying to pioneer ways to link people with their natural environment - especially people with health problems.

**Berni Shine** I love that idea..its a real dilemma for people with chronic illness. One that it's hard to find answers to. Some kind of outreach maybe attached to primary health care. A creative presence. I have also liked the idea of dedicated centres around the country..offering all the facilities needed...is it a dream?!

**Art Gene** What would the dedicated centre involve? What would this kind of dream centre look like and have in/ around it - everyone please do contribute!

**Art Gene** (contribute)

**Gwen Kennedy** Have been involved in putting Cork City Access guide together think its still on cork city council website though its now 15 years old but everywhere referenced was visited by somebody with some form of physical or sensory disAbility with questions relating to all including hearing aid loop , visual prompts ,ramps ,level access etc...

**Berni Shine** It would have medical people as well as therapist, aromatherapy, massage, physio... chat rooms.. places to lie down. Comfortable chairs. Creative spaces.. ive thought about it often. It's hard to get chronic pain on the map...but anything is possible with the right will...

**Art Gene** Berni, this whole conversation is contributing to researching how to facilitate people with mental and physical health problems accessing our local (wonderful) natural environment. We consider problems in new ways - starting with people's dreams!

**Ciara Chapman** **Art Gene** I love this! I think the most inspiring thing for me is watching videos by Sia- the combination of the music and the dancer she uses leave me awestruck! There's something very special about winning combinations like that that make me really believe things happen for a reason!

**Ciara Chapman** **Art Gene** very well put Ruth

**Berni Shine** I had the opportunity to attend an Arts therapy course in Tallaght last year. It was run in conjunction with chronic pain Ireland and \*Arts for Health\* WHICH is a great organisation. They do great work in promoting art of all types ..enabling access for people with chronic illness. I think from a policy point of view government could tap into the role creativity has in helping people recover from illness and as an on going resource. I hope I am making sense. Chronic pain also ran a writing course a few years ago. I personally find that been part of a group and having goals and a focus helps to improve my quality of life

**Corina Duyn** I so love your work Ciara. It explains in a very gentle way, the huge challenges of chronic pain and illness. In this piece I recognize the ever dance with life, with pain, and yes, although physio is suppose to help us, it often does not- at least that is my personal experience. Be well. And stay creative!

**Ciara Chapman** Thanks so much **Corina Duyn**! I think I would be doing the group a disservice by not asking you to post a pic of your extraordinary puppets.

[Image posted by Corina]

**Corina Duyn** **Art Gene** added a photo of my current work, see above. Thank you!

**Corina Duyn** Thanks Ciara. Here a picture of them fully dressed but not yet strung up. Their story is that one is standing with her walking sticks in front of a mirror , but in her reflection sees herself dancing.

**Ciara Chapman** **Corina Duyn** awwwe I adore these little women and your amazing ability to create them!

**Corina Duyn** Thanks Ciara. they do take a long, long time to make, as I only work a short time (20 min is best), but eventually they are there! A joyous moment.

**Gwen Kennedy** Have you had a clip of this on you tube **Corina**? or in a book love this idea

**Art Gene** Where do you exhibit your work Corina? Everyone? I guess you know each other - or at least each other's work well. Have you thought about exhibiting together? Is that something that Chronic Pain Ireland could assist in?

**Corina Duyn** Gwen, I have lots of my previous work in books, and some in film, and on my website/blog, These two puppets will be filmed in the next few months. I do have a little film I did with other people with disabilities. Called 'Life outside the box' . I can forward links if you like? Thank you!

**Gwen Kennedy** 10-15 of us were talking about it last week exhibit in 2018 maybe

march/april time through Lets create and share page I set up

**Gwen Kennedy** Love to see it Corina

**Corina Duyn** Ah, I'd Love to be involved in an exhibition. Thank you. My website (with link to my personal blog, and a link to the Puppet blog) is [www.Corinaduyn.com](http://www.Corinaduyn.com) . Please share Facebook page link?

**Gwen Kennedy** I can add you to the lets create page ...

**Corina Duyn Art Gene** I have had exhibitions, but share most of my work through my website/ blog and in my (artist) books. I love the ideas of a group show.

**Gwen Kennedy** Done your added

**Corina Duyn** **Gwen Kennedy** please do add me, thanks

**Gwen Kennedy** Ive had exhibitions through Bealtaine (May) Festival with Libary art group I go to...for the last few years Im one of the youngest members at 38 !!

**Corina Duyn** Ciara, see , your drawing of dance, of movement brings movement of a different kind. A sharing of our experiences. Our creative experiences. The added bonus of creative work. Thank you!

**Berni Shine** Those puppets are beautiful Corina..i love the detail.

**Ciara Chapman** **Corina Duyn** stunning!

**Berni Shine** When you have cp..it can be hard to meet up..that is a sad part of this condition. Thankfully forums help us to stay connected.

**Gwen Kennedy** Indeed speaking of meeting up planning on heading to **Ciaras** exhibition launch tomorrow evening @6.30... will also be in Dublin either next week or week after planning on going to 25th anniversary CPI event anyone else coming to either ... if not will be in Dublin for a few days at least a few days before or days after if anyone fancies a cuppa and a doodle or seeing some exhibit ...

**Corina Duyn** **Berni Shine** thank you so much

**Berni Shine** It's been great chatting to you. Make a me feel a little less isolated.

**Ciara Chapman** **Berni Shine** thanks so much for getting involved Berni, it's great to hear your point of view 🙏

**Frances Heneghan** **Berni**, it's time you disclosed more of your art!

It looks intense, I would think it demands immense physical energy, but also a release?

**Gwen Kennedy** Here here

**Berni Shine** Did this while on respite..

[Image posted by Berni]

**Ciara Chapman** Wow Berni! Is it pen and coloring pencil?

**Berni Shine** Yes ciara.. I think of it as a kind of doodling..but it's amazing how it reveals it self..

**Berni Shine** Your writing is so thought provoking Frances. I love your writing. . I think it can be hard to maintain creativity at times..when pain and tiredness take over. It's important not to feel pressurised..which is something that happens to me. I recently finished images for a poetry book..which my sister wrote ..it was challenging but I felt a great sense of achievement.

**Frances Heneghan** Difficult to tread the tightrope between creativity and pain causation, **Berni**. Pain definitely shortens creativity time, always more mundane activities intervene!

**Berni Shine** So true Frances..

**Berni Shine** Another piece..obe I did for poetry book..its not going in..contrasting good and bad days

[Image posted by Berni]

**Frances Heneghan** Such gentle colour, beautiful contrast, **Berni**.

**Gwen Kennedy** This really pops

**Gwen Kennedy** Does anyone else here dream in images and then sketch or paint or write about those dreams?

**Gwen Kennedy** How about you **Frances**?what have you been up to creatively speaking?

**Frances Heneghan** Trying my hand at photography, **Gwen**, and writing. I was a voracious watercolour painter but haven't painted since losing most of the power in right hand. Hopefully, that will be sorted - my easel awaits!

**Gwen Kennedy** Its good to talk have been trying to sew and knit and have written a bit for 1st time in 11 /12 years...

**Frances Heneghan** I had to drop knitting and sewing, **Gwen**.

I've gone from scenic views to smaller images, I'm practising b/w and light-intensive. I couldn't travel to a professional course, so I experiment!

**Gwen Kennedy** Love photography also

[Image posted by Gwen]

**Frances Heneghan** Comforting colour in Autumn, **Gwen**.

**Gwen Kennedy** Well its a cliché but a picture represents 1000 words 😊

**Gwen Kennedy** What have u been photographing **Frances**?

**Frances Heneghan** **Gwen**, I find I'm portraying isolation, which **Ciara** mentioned earlier. Strangely, I didn't realise that until now!

**Gwen Kennedy** Experimenting hands on is good will you share a photo or 2?

[Image posted by Frances]

**Gwen Kennedy** I love the reflection its shadowy....

**Frances Heneghan** I didn't realise I've been going in this direction, **Berni**. The mind goes where it needs to...

**Corina Duyn** Interesting conversations. Thank you **Ciara** for inviting me. I will catch up later with further comments. Computer time is up for the moment. Be well everyone, and stay creative.

**Frances Heneghan** Many thanks, Art Gene and those who partook in the conversation base on **Ciara Chapman's** work. I hope we meet up again in future.

**Berni Shine** Yes thanks to **Costa** and Art gene. It was very interesting to be part of this conversation.

**Berni Shine** Sorry **Ciara**...

**Gwen Kennedy** Here here

**Gwen Kennedy** Thanks **Artgene** and **Ciara**

Thanks [Artgene](#) and [Ciara](#)

14th November, 2017

Image posted

**Art Gene** Hi [Ciara Chapman](#)! I've led with this image as it asks a pertinent question for everyone as to the extent we are our bodies - we will all age and be let down by our inherent physicality in some way. But I guess for you, your illness can feel like it has taken you over or forced its way into being part of your personality. Can you tell me a little about this? Is it avoidable?

**Ciara Chapman** It's so true Ruth! I've found myself pausing briefly from time to time and thinking to myself 'is this me?' I often say I feel like an old woman, people laugh as if I'm joking but I'm really not- this is exactly how I imagine an elderly person feels. I was a bit of a people pleaser before- only too happy to sacrifice my happiness to please others but this experience has taught me to be a much better version of myself. I'm less judgmental, less eager to make others happy and more calm in myself. Aside from the unbelievable pain I feel and lack of mobility, I'm a lot happier in myself than I've been since I was a child. Pain gives a clarity you would never expect!

**Art Gene** Once again, I could never have predicted your answer. I wonder if that is how others feel? I follow you completely on being less judgmental - as I guess when your priorities change in life, so do your systems of being with people and needing people. Your calmness surprises me, but when dealing with pain, your only weapon is skilfully mastering your mind and emotions.

**Matt Sanderson** Hi Ciara, again you've hit the nail on the head.

Pain focusses the mind; once I got past the introverted viewing that it caused, my whole outlook on life changed. Very similar to your experience, in many ways I am considerably happier than I was as this was all developing (and even before).

I'm not saying we should accept our lot, but a certain acceptance of ones condition reintroduces foresight and a desire to look ahead, rather than dwell on the painful past.

**Art Gene** What about the fatigue associated with a chronic condition? Isn't that just numbing?

**Ciara Chapman** [Matt Sanderson](#) very very true Matt. I used to agonize over past decisions and stress about future ones but now I'm forced to be present. I'm hopeful about my future but I'm not consumed by anxiety about it. I take everything much slower now. I had lots of people in my life before I became unwell and only a handful now in comparison but the people who remain are all the best ones. Even though at times I feel sorry for myself, I'm so grateful for a lot of my life now.

**Berni Shine** Hi ciara.. interesting what you had to say about how your life and perspectives change with cp. It's a long process of acceptance..which varies over time. I do think it takes time and patience.also access to supports both in the community and among friends and family. I'm not sure if I'm happier ...ive certainly changed in my outlook to life....

**Berni Shine** And yes the fatigue is outrageous

**Art Gene** Hi Berni! Thanks for joining us today.

**Art Gene** Can you all tell me about the people in your lives. Do you find yourself constantly explaining what is happening to you? Or do they get it. Do you have relationships that manage to be separate from your illness?

**Ciara Chapman** **Art Gene** I've found it really hard to explain to family. My friends are very accepting. In my family if there's something wrong, you go to the doctor and get better so this experience of waiting for a diagnosis is something that still doesn't seem to sit well with them but they are really trying to understand so that's very important.

**Ciara Chapman** **Berni Shine** for me in my old life I was headed towards a nervous breakdown- honestly- so I think if this medical issue hadn't come along it would have been something just as severe mentally to force me to change.

**Berni Shine** That's a tricky one Ruth.. most people are used to my situation..family and friends.. but I sense there can be a weariness among them. I imagine how it feels. I also have family members with cp..so that's strange. They are at a different stage than me.

**Ciara Chapman** **Art Gene** fatigue is awful! Too sore to sleep, pain dreams come when you do and then it starts to make me feel anxious about going to bed altogether which just perpetuates the loop.

**Art Gene** **Ciara Chapman** - I guess your family are just waiting for a clue as to what they can do, practically to help you. Like make chicken soup or something. Yes, it is good to have soup when ill, but that gesture is also about the person making the soup feeling useful. It must be horrible not being able to help.

**Ciara Chapman** **Art Gene** I think it must be. They're crying out to help but the only thing I can ask them to do is to be patient and that's probably the toughest thing they can do. I don't think they realize that they're actually already doing everything they can to help.

**Berni Shine** I have very kind and patient friends.. there are days when I am so irritable and find it hard to be human. That's something I have to work on. I had one of those nights of weird dreams...i often dream I can't see. And I'm aimlessly trying to find my home...very scary.

**Berni Shine** Ciara...i had quite a lot of anxiety related issues for many years prior to my surgeries. Because of my chronic illness I've had to take stock...i wonder what way my life would have gone. I don't want to swap with anyone.. we all have challenges. This is mine. Sharing our stories can only be a good thing. Ciara I hope what you do is helping you ..its a great outlet. I really enjoyed art therapy. It would be great to see it been run again.

**Art Gene** **Berni Shine** and **Ciara Chapman**, We talked a bit last time about making art and how it could help you in many ways - including Art Therapy. What about looking at art, reading or listening to music - or other art forms. Do you find you have more interest in it now, or less?

**Berni Shine** **Art Gene** I would say that I appreciate reading a lot. For some strange reason I don't listen to that much music. I go through phases with books, but find them great company. I used to go to so many exhibitions...and openings..a lot of my friends are artists. But I don't as much now. It can take supreme effort, often worth it though. Honestly I feel very self conscious at times ..but you do get used to it. Standing is not sustainable and there is always the worry that you might not find

a comfortable chair. These are day to day realities. They are not all consuming .....  
**Ciara Chapman Art Gene** for me even the art I made before being unwell was rigid, I didn't want to share anything personal or important to me. It was about 9mths into having sciatica that I started my diary. I was lying on the floor watching dancing on tv and I thought 'imagine being a dancer in my position ' I started drawing emotions rather than just people. It released an anger that was building in me. I honestly think if I didn't draw my feelings I would be a very bitter person. There's something about focusing on what's bothering you, getting it down on paper and finishing it that releases the emotions- for a little while anyway. I don't want to even think about what this experience would be like without any outlets at all.

Image posted by Berni

**Ciara Chapman Berni Shine** love this! So pure and beautiful  
**Berni Shine** Its part of a piece from Art therapy about the contrasting sides of pain...or an alternative state away from pain..

Image posted by Berni

**Ciara Chapman Berni Shine** it's gorgeous Berni- so delicate. Almost Christmasy  
**Berni Shine** Ciara i really relate to what your saying about releasing emotions...I never know what is going to happen when I start something...but when I let go of ego...just be myself, then it releases something.

**Ciara Chapman Berni Shine** I think that's what I've found very important in this experience. I overly cared about what people thought before and now I don't care too much. I wouldn't step outside the box in case it offended someone or something and now I don't care because I'm making art for me, to help myself and get myself through this week into next week. It's exactly as you say- letting go of ego!

**Art Gene** So for you both, making art is very, very necessary to your health and wellbeing - almost replacing the place of traditional medicine.

**Berni Shine** I suppose there is an element of truth there. I didnt think of it that way. Its something that could be developed more ..the integration of creativity into medicine as a tool to help with recovery ect. There are projects and organisations..like Art Gene out there. WE need to have an integrated approach...I,m wondering a bit now! So tired. I would be lost with out a creative out let...but there can be other ways of getting release when you have a chronic illness. I am so grateful for it. This chat this morning had made me see how important it is, thank you for that. Thank you Ciara..you are so inspiring.

**Art Gene** Do you think Art Therapy can reach/help most people? Or is it for people who have already a strong interest in art?

**Berni Shine** Ciara and ART Gene just want to say bye for now....exhaustion taking over. It was so good chatting to you today. It would be lovely to do it again soon.

**Ciara Chapman Berni Shine** I don't know if that's true, I'm doing things for my own well-being and sharing work is part of it. I'm very grateful if it's inspiring anyone but I think that's a compliment that I don't feel I've earned. I think as you say creativity alongside medicine is something that needs to be looked into more but I know myself without medication I couldn't draw a thing so I don't see it as a replacement,

it's another facet of the healing process. Creativity helps the mind and improves dexterity- that's priceless.

**Ciara Chapman** **Berni Shine** thanks so much for taking part Berni, your work is so beautiful 🥰

**Matt Sanderson** **Art Gene** I think if you (not you personally!) restrict your perceptions of what art is, you restrict people's interest and potential benefits. If people are encouraged to see the art in the everyday, then the benefits can be limitless 😊

**Berni Shine** Regarding Art therapy helping people...yes I definitely believe it can. It is a therapy...that helps to tap into emotions. A means of expression of telling your story. There are no rules...just be yourself.

**Ciara Chapman** **Art Gene** I think a lot of people have a mind block when it comes to creative outlets. They say to themselves 'I'm not good at that' but there are so many different types of art. Some people love getting their hands on clay, others love knitting and embroidery, there are so many different forms of painting alone, even the amazing puppets that Corina shared last week- they cover all of the above. You don't even have to share it with anyone, just do it for yourself! I've been art focused for 20 years now and it's only in the last couple of years I'm comfortable sharing it- but that doesn't mean I wasn't making it all along.

**Ciara Chapman** **Matt Sanderson** so true Matt! Art is everywhere, so is creativity. My physiotherapists have been so creative when it came to my therapies!

**Art Gene** **Matt Sanderson** - I guess that's where the connecting people to the landscape in multiple and creative ways comes in...

**Berni Shine** **Ciara Chapman** I often find it hard to receive compliments as well about my art....What you are doing is of course for you...but by sharing your story you are helping people to understand what pain feels like.

**Ciara Chapman** **Berni Shine** thanks so much Berni! You're so kind!

**Ciara Chapman** Thank you so much to everyone who took part in today's discussion. There were some really interesting points from Matt and Berni and beautiful pictures from **Berni** too.

Another big thanks to Ruth and ArtGene for this opportunity, I can't believe the month went by so quickly. I'm looking forward to seeing the next artist for Digital Gene Pool, it's a great project!