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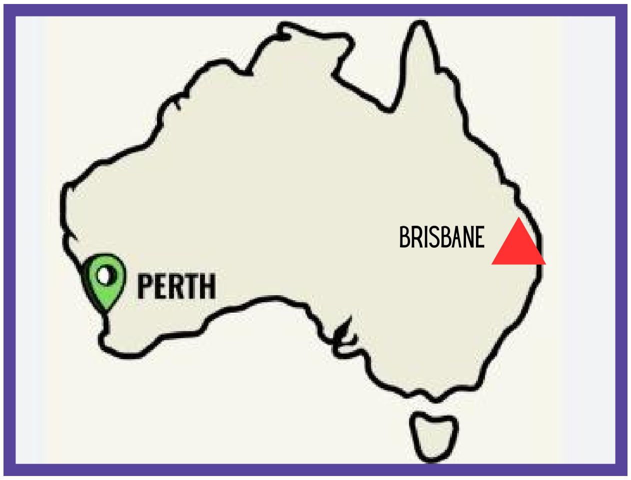
Newsletter

WALK 4 PICS



INTERNATIONAL Walk 4 PICS

Welcome to our special international edition of the Walk 4 PICS newsletter!

This month, we're uniting across borders and time zones to recognize the global impact of Post-Intensive Care Syndrome (PICS) and to celebrate the strength and resilience of survivors worldwide. Whether you're a survivor, caregiver, clinician, or advocate, you are part of a growing international community that refuses to let PICS go unnoticed.

In this special edition, we're highlighting survivor stories from around the world, spotlighting research and advocacy efforts on a global scale, and offering tips and resources that connect us across cultures. The need for awareness, support, and compassionate care is universal.

Around the world, survivors of critical illness face similar challenges after ICU stays—whether it's identified as PICS, ICU delirium, post-ICU cognitive impairment, or another term entirely. No matter the name, the impact is real, and so is the need for awareness, support, and connection.

In this special international edition, we're recognizing the diverse ways countries and communities understand and respond to the long-term effects of intensive care. From survivor stories across continents to innovations in post-ICU care, our goal is to build bridges, share knowledge, and strengthen a global community of resilience. Recovery doesn't end at ICU discharge—and together, we're making sure that truth is heard worldwide.

In this newsletter you can expect:

Walk for PICS Team

PICS Provider Spotlight

Dr. Xavier Fiorilla, PhD
Research Coordinator
Sir Charles Gairdner Osborne Park
Healthcare Group

ICU Survivorship. When the going gets tough. Where the research and practice intersect.

Contributors: Xavier M. Fiorilla, Matthew Anstey, Bradley Wibrow, Bhaumik Mevavala

In January 2023, I joined the Intensive Care Unit Research Team at Sir Charles Gairdner Hospital in Perth, Western Australia, as ICU Research Coordinator—a role I share with my colleague, Bhaumik Mevavala. Under the leadership of our ICU Research Co-Leads, Dr. Matt Anstey and Dr. Brad Wibrow, I stepped into a position that allowed me to witness not only the intensity of critical care, but also the quieter, often under-recognized phases of recovery that follow.

Sir Charles Gairdner—affectionately known as "Charlies" by locals—serves a vast region, with patients arriving from some of the most remote corners of Western Australia. It was in this context, in July 2023, that I first encountered Post-Intensive Care Syndrome (PICS). I had been asked to relieve Bhaumik during his leave and assist in coordinating our ICU Follow-up Clinic. My initial task seemed simple enough: identify recently discharged ICU patients and schedule them for review. What I didn't anticipate was how profoundly these follow-up conversations would shift my understanding of what it means to recover from critical illness. That first clinic day opened a door into a world of unspoken struggles—and sparked my determination to ensure that ICU survivorship stories would no longer go unheard.

What made you choose the path of working with PICS patients and families?

There was a moment early on in the ICU Follow-up Clinic that will stay with me forever. A woman who had survived a major stroke came to the clinic accompanied by her husband. As she sat across from me and one of our ICU consultants, tears welled in her eyes. Through sobs, she asked, "Why did these doctors save my life? I'm useless. I should have died." That moment was profoundly unsettling—not only for us as healthcare professionals, but I can't begin to imagine how heartbreaking it must have been for her husband to hear those words. It was the first time I truly grasped the emotional and psychological weight that ICU survivors—and their families—carry long after discharge.

That day changed me. I realised that Post-Intensive Care Syndrome doesn't just affect the individual—it ripples out to loved ones, caregivers, entire families. And it's not enough to save lives. We must also help people live them. That's why I chose this path. As I often say: "When the going gets tough, that's where research intersects clinical practice." We need to follow up with survivors, understand what they face and help improve their recovery, only then can we ask the right research questions. When guided by lived experience, research becomes a tool not just for understanding, but for uncovering real solutions to the challenges survivors face.

What do you think is the biggest misconception about PICS?

One of the most persistent misconceptions about Post-Intensive Care Syndrome (PICS) is that it's somehow not "real" or not the responsibility of ICU teams—perhaps because it doesn't come with an ICD-10 diagnostic code or an easily measurable treatment. It doesn't fit neatly into a clinician's toolbox. Some intensivists may feel, "This isn't something I can fix," and many general practitioners haven't even heard of it. In fact, a 2022 Australian survey of 60 general practitioners found that 80% had never heard of PICS in paediatrics, and 93% were unaware of any educational materials. Our own team, led by Dr. Matthew Anstey, recently found that only 6 of 207 adult ICUs in Australia offer a formal ICU Follow-up Clinic, and just one in New Zealand—for paediatrics.

At Sir Charles Gairdner, we've been trialling a multidisciplinary Post-ICU Clinic since 2021. Every fortnight, a team of 18 rotating ICU consultants identifies high-risk survivors and links them to physiotherapy, psychology, and GP support. The feedback has been powerful: survivors feel seen, clinicians feel reconnected to long-term outcomes, and we're all reminded that ICU discharge is not the end of the story.

But here's the challenge—there's still no consensus on how to structure these clinics or which tools to use for screening. The literature offers mixed results on their effectiveness, but perhaps that's because PICS can't be treated with a one-size-fits-all model. Every patient is different. Applying the same follow-up strategy to everyone risks missing the mark entirely.

In my experience—and in conversations with colleagues across Australia—patients often say they feel abandoned after ICU. No one talks to them about their cognitive fog, nightmares, or depression. They don't know where to turn. What they need is someone who can help put the pieces together—someone who can explain what happened, what's happening now, and what might help them move forward. So yes, it takes effort to follow up. And yes, it's resource-intensive. But is it worth it? Absolutely. For many, it's the first time someone acknowledges that their suffering is real—and that they're not alone in it. It's worth it because it gives survivors a language to describe what they're going through, a team that validates their experience, and a path forward when they've felt lost in the aftermath.

It's not just about improving clinical outcomes—it's about restoring dignity, agency, and connection at a time when many feel forgotten.

What advice would you give to someone who is newly diagnosed with PICS?

First, please know this: what you're going through is real—and you are not alone. Post-Intensive Care Syndrome can be deeply debilitating. Many survivors tell us they feel guilty for not being able to "bounce back" or return to being the parent, partner, or professional they once were. They feel they should be grateful for surviving—but instead, they're overwhelmed, anxious, or exhausted in ways they can't explain. That tension between surviving and truly living can be heartbreaking.

Don't try to do this alone. One of the most important steps you can take is to connect with health professionals who understand PICS—whether it's through a hospital-based follow-up clinic, your GP, a psychologist, or a physiotherapist. Look for a multidisciplinary team if possible, because PICS is complex and it affects the body, mind, and relationships.

Also, if you can, seek out educational resources or local peer support groups. Talking to others who have walked this path can help you begin to reshape your "new normal." One such resource is mylifeaftericu.com, a website created to support survivors and families through their recovery journey. It was developed through the leadership of Dr. Matthew Anstey, Dr. Bradley Wibrow, and colleagues nationwide, inspired by the story of Kirsten Anne Collins, a young woman who passed away in our ICU at Sir Charles Gairdner Hospital. Her family's donation helped turn their vision into a national platform.

What message would you like to share with survivors who feel misunderstood in their recovery journey?

If you feel lost or misunderstood after ICU, please know that what you're experiencing is more common than most people realise. Many survivors carry invisible wounds.

My message is: be patient and kind to yourself. Recovery isn't linear. Some days will feel hopeful, and others will feel heavy. That doesn't mean you're going backwards—it means you're healing.

Balance rest with small daily steps. Routines can slowly rebuild confidence. Surround yourself, when possible, with people who listen without judgment—whether they're health professionals, peer groups, or family.

And if you haven't found the right support yet, don't give up. There are people out there who understand this journey—people who have lived it and come through it. You don't have to figure it all out alone. Share your voice. Make sure your healthcare provider understands what you're going through. PICS is still not well known in many settings, and your experience matters.

What are your hopes for the future of PICS research and survivor care in the next 5 to 10 years?

My hope is that in the next decade, Post-Intensive Care Syndrome (PICS) becomes a recognised and routinely addressed part of the recovery process—not something survivors have to explain or navigate alone. We need to raise awareness, especially among general practitioners and ward-based teams, so survivors aren't falling through the cracks the moment they leave ICU.

We also need sustained funding for structured follow-up programs. These clinics shouldn't be the exception—they should be standard. That requires national coordination, including how we screen, refer, and connect survivors to the right support at the right time. A critical step toward this is the establishment of an official diagnostic code for PICS. Without it, we can't track the scale of the issue, allocate resources, or deliver consistent care across the system.

We need more research—not just to understand PICS better, but to identify what actually helps. Which interventions make the greatest impact? How do we tailor follow-up care to the individual, rather than applying a one-size-fits-all model? Predictive models—when combined with clinical care—could help us anticipate which patients are most at risk and personalise support accordingly.

And as we advance research, it's essential that we make it more inclusive. People with pre-existing mental health conditions, or cognitive impairments are often excluded from trials—yet they may be among those most affected by ICU recovery challenges. Their experiences must inform our understanding of what care looks like after critical illness.

Sir Charles Gairdner Hospital outside Perth, Australia

PICS Impact Stories:

This month we would like to spotlight a few international PICS survivors.

Mette Bang Jorgensen (Denmark)
Mette is a survivor of acute pancreatitis, sepsis and organ dysfunction. Mette will be five years post ICU this October.

Tell me what sent you to the ICU.

I started to present with jaundice and went to the doctor for some tests that sent me to scans and they showed that a stone was stuck in the lower part of the gallbladder. I was sent home to wait for the procedure; during that time I had two online job interviews and landed the position. The simple and same-day procedure to retract the stone resulted in acute severe pancreatitis with multiple organ dysfunction and sent me to the ICU. Over a couple of days, I went from being excited and just having to get the procedure done to being acutely critically ill, barely being able to walk. The day I was to start the position I got discharged and sent home to recover.

What brought you to the ICU group?

After coming home, I slowly started to regain muscle and restore a little energy due to the support system of weekly physiotherapy lessons, home exercises, and what seemed like continuous endurance training outside with the walker. As my body slowly got better, my mind started to struggle and started to process the trauma. I searched the internet and found resources online in the form of a podcast about the ICU and learned about PICS. To my surprise the podcast had an episode with a fellow survivor who also had suffered from SEPSIS and pancreatitis.

This was the first time I had heard a survivor tell their story and I instantly felt how important it is to share in order to connect and learn how to master the individual situation we are left with post ICU. The podcast host offered to connect me with the survivor; he knew about the PICS 101 group from the CIBS Center at Vanderbilt and helped me sign up.

How has being a member been for you?

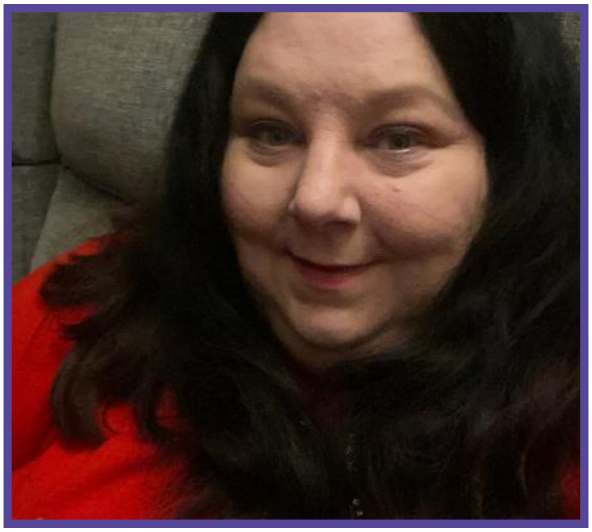
What amazes me is how giving it is for me to have a community. Despite the very different reasons we have for ending up with PICS, we can mirror each other and all contribute to the community in the way we can. I have and continue to meet strong survivors who share the struggles of living with PICS. The meetings are a beautiful mix of inside jokes, deep conversation about difficult topics, and witty banter. But the community, immense understanding, and sympathy for each other are the reasons I start the laptop every Monday night.

I am so fortunate to have found a community that I could not find in my home country and although I am based in the Central European Time zone and the meetings are at night, it works for me.

What do you want others to know about PICS?

There are many variations in how PICS can present itself and sometimes patients are recovered physically and still have hidden struggles. It is important for medical professionals to know the fine balance between a technological medical environment of the ICU and providing humanized care for the person tangled up in lines and monitoring equipment.

It is a common thought that after discharge you recover and go back to normal. The truth is recovery is a long haul, and the real challenge begins at discharge. Most end up having to adjust to a new normal. The life crisis that critical illness and PICS can result in can have a tremendous effects on both survivors and our families. It is important to advocate in order for us to understand how to secure the best possible offset for recovery and empowerment for survivors.



Abi Hagger (UK)
Abi is a survivor of ARDS

What do you want people to know about you outside of PICS?

My name is Abi Hagger. I'm 51 years old and from the UK. I've been a Career Adviser (guidance counsellor) at a local college for 23 years. I live with my partner and 3 Jack Russell dogs in the North of England and I have a 20 year old daughter who is away at university. I am disabled, use a wheelchair, and use supplemental oxygen.

Tell me what sent you to the ICU?

In early December 2010, I was admitted to ICU with swine flu and double pneumonia. This caused me to suffer ARDS and I was put in an induced coma. After a few weeks I was sent to another hospital to be put on a type of life support called ECMO. After being taken off this machine I was brought out of the coma. I woke to find I was paralyzed, hooked to various machines, and was breathing through a ventilator in my trachea. I had no memory of what had happened to me. I was transferred to the ICU at the hospital near home where I spent another couple of weeks. I was eventually sent to a respiratory ward and then sent to my parents' home to recuperate.

What brought you to ICU support group? How has being a member of the group helped you?

In the UK I haven't found an ICU support group and in fact, the term PICS was fairly new to me only a few years ago. I know from experience, however, that being part of a support group is so important. It stops you from feeling alone. I set up a Facebook group when I came out of the hospital for those who had been on ECMO, as I had no information about what to expect with regard to symptoms and recovery. I was unaware of what PICS was or PTSD but I suffered with them. Learning how ICU has affected other people and listening to their experiences helped me greatly to understand what I was going through. It was reassuring.

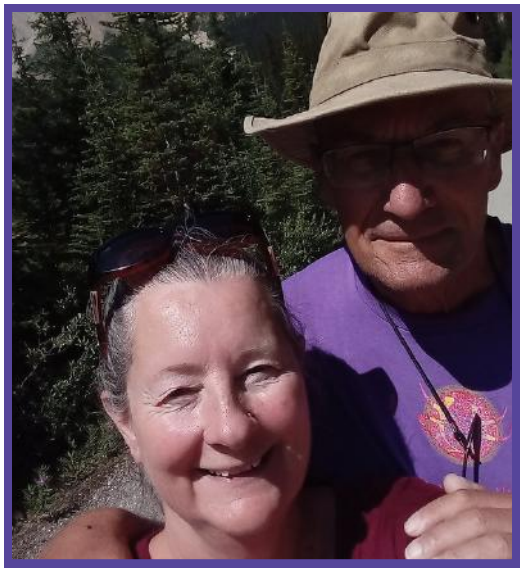
What made you want to be involved and be an advocate with Walk for PICS?

I am keen to share my experiences in the hope that it will help others who are going through this. Although I have disabilities now, at the time of my recovery I learned to walk again and breathe again. I had muscle weakness, lost hair, and had cognitive issues for some time but I found the psychological effects the hardest to deal with. However, in the years following I was able to regain strength and go back to the career I loved. I have had a lot of therapy which has really helped with my PTSD. My cognitive abilities improved greatly and I was even able to achieve a post graduate degree in teaching.

The reason for my disabilities now is that unfortunately I was hospitalized with covid in 2021 and it has left my lungs damaged and my mobility minimal. Although being back in hospital was scary, I found that I was more resilient than I expected and didn't suffer psychologically as a result.

What do you want others to know about PICS?

I would like other sufferers of PICS to know that there is hope and it is possible to live life to the fullest, even if that means making some adjustments. It is important to get support from loved ones and friends and to educate them about PICS. Get information and support from organizations like this one. ***You are not alone!***



Denise and Gene Roach (Canada)
Gene is a survivor living with PICS

What do you want people to know about you outside of PICS?

I am a forester by training, love the mountains, forests, hiking, history of their exploration, genealogy, love reading almost any non-fiction, and am a born and raised Albertan!!!!

Tell me about what sent you to the ICU?

In late December 2022, I had a minor sinus cold. December 30, I had a grande mal seizure at home. I was in the ICU in a medically induced coma, tested positive for RSV and negative for covid. I had received the flu and covid shot that fall. There was no history of seizures in me nor my family. Although there was nothing definitive about how this happened, it was thought the sinus cold moistened the nasal passages, compromised my immune system, and RSV took advantage of that. Where the seizure came from was not clear.

What brought you to ICU support group?

At discharge I was given no information on what I might experience at home. Let me emphasize that....nothing. Not even a five minute chat about some symptoms I might experience mildly or severely, short or long term. I was instructed to contact my family doctor for follow-up.

My spouse in researching delirium stumbled on PICS. She printed the symptoms information, handed it to me, and I said “that’s me.” My research on PICS led me to Vanderbilt and the support group.

How has being a member of the support group helped you?

- Connect with others about similarities, differences, impact on them/family life and living
- Hearing the stories makes it more real that I am not alone
- Reassurance that I am not crazy
- Email connections for sharing information, experiences, questions, discussion, support

What made you want to be involved and be an advocate with Walk for PICS?

I definitely want be involved and advocate for PICS. The first Christmas after my discharge, I went to the ICU and personally thanked them for saving my life. I wanted to look them in the eye and know how grateful I was, and that I was doing very well overall. I took the opportunity to inform them we got no information about PICS at discharge, not even mentioned. And I asked them about creating a brochure, something simple and specific of what might be coming, and the length, breadth and impact it might have on them and family. I have talked with the manager four times and given them a Vanderbilt brochure. No progress yet.

I'm unsure about launching a local Walk 4 PICS. I have not found a PICS survivor in the community I live in. I contacted some radio talk shows that do this sort of thing occasionally. They are all into the higher profile stories. But I will keep trying.

What would you want others to know about PICS?

- It’s real and can be very serious!!!!
- It affects all ICU survivors, families and friends. The only differences are about for how long and how impactful on quality of life.
- There is help and support.
- Simple actions can make a significant difference; going for short walks, meditation, yoga, practicing gratitude and self compassion, hydration, healthier eating, staying connected to friends and family, simple exercises (for balance for example).

Jackie and Miles Negus-Fancey (England)
Miles is a survivor of Avian flu, pneumonia, strep A, sepsis, multiple organ failure, and severe ARDS. He was in a coma for 57 days and in the ICU for 90 days in 2016. He learned he had chronic lymphocytic leukemia.

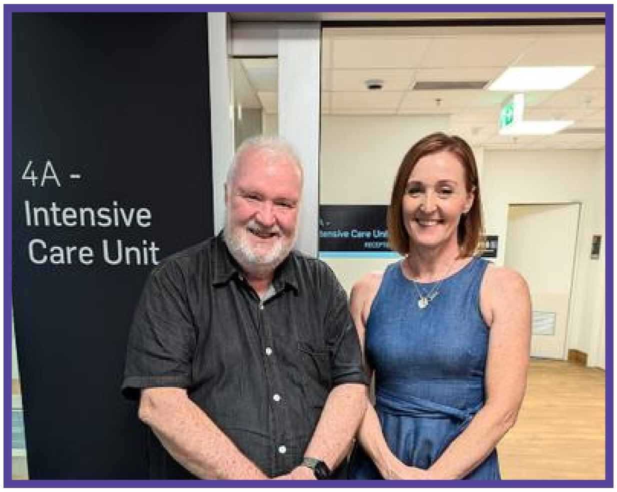
What do you want people to know about you outside of PICS?
I am a parent & grandfather, a decorative artist, specializing in mural, gilding and Venetian plastering. I am a beekeeper, owner of dogs, and chair person of the Critical Care Support Network.

Tell me about what sent you to the ICU?
I had double pneumonia, strep A & avian flu. I had multiple organ failure, sepsis which had become septic shock as I entered ICU. I also had EBV, CMV and glandular fever. Whilst in ICU, I caught MSSA & VRE and overcame severe ARDS. They also discovered I had Chronic Lymphocytic Leukemia.

What brought you to the ICU Support Group? How has being a member of the support group helped you?
I joined the PICS group so that I could become a 'member' of a group as opposed to a facilitator (which has been my role for 9 years with CC-SN).

What made you want to be involved and be an advocate with Walk for PICS?
Raising awareness is so important because ICU patients' plight is so misunderstood.

What do you want others to know about PICS?
That ICU will change most of us forever - how do we best rebuild from the wreckage of our past?



Thoughts from Kim Austin (Australia), a survivor of Pneumocystis jirovecii pneumonia, and ARDS. Kim will be 4 years post-ICU this October.

My name is Kim Austin, a male of 68 years living on Bribie Island, about 80km (50mi) north of Brisbane, the capital of Queensland, Australia. Before hospitalisation, I was working online from home. When discharged in late 2021, I medically retired due to a number of issues that remain to this day. I also lost the ability to engage in my favourite passion, photography. I've had to change my life, which has been extremely challenging.

When I became sick, I thought I would go to a local hospital, but discovered when I was extubated 10 days later I had been transferred to Queensland's major hospital, Royal Brisbane & Women's Hospital. After ICU I spent a further five weeks, including rehab. I had been admitted with a very dangerous form of pneumonia that primarily affects immunocompromised individuals, which I am. I also had ARDS. I received excellent care during my stay, and I am forever grateful to the nurses, doctors and other specialists who encouraged me to be positive as I tried to walk and see again.

I came home and struggled finding support. Post-ICU support was only available to patients at Royal Melbourne Hospital, so I went out to the world looking for some way of talking to others who were experiencing things that I now know to be PICS. I struck gold when I found an online group in the UK called the Critical Care Support Network. I remain a member, and get a lot from the support it offers. A year ago, I also found the PICS 101 group at Vanderbilt. It helped me so much, and continues to do so to this day. I have made good friends there, all of whom understand the frustrations I have. Finding a community of caring people with similar lived experiences has been amazing.

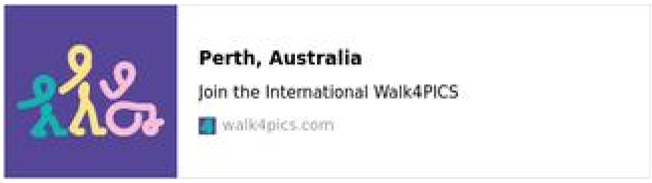
One thing I want others to know is that help is out there. PICS-based groups are springing up around the globe, because survivors persisted. Though many medical professionals know nothing of PICS, there are others who do and they are leading the way to provide better support. Also, as much as we would like a fast recovery, it may not happen. Each case is different, but most survivors will find they have with new challenges. Certainly that is what I found, and almost four years on, my recovery is very slow.

Newsletter Insights

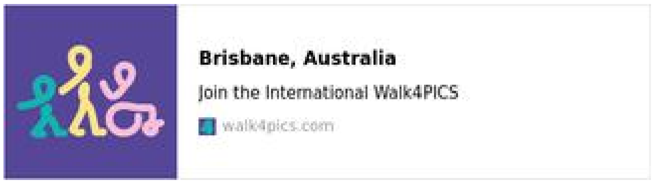
We have organized a simple walk of any distance to challenge our bodies while raising awareness of this complicated syndrome. Individuals can walk anywhere in the world, either on their own or with loved ones. It is our desire that every ICU survivor living with PICS knows they are not alone and that there is hope and support for their journey.

If you can’t walk on September 27, walk any day in September. Walk wherever you are, for as far as you can.

Click the interactive links below for to learn more about the walks in Perth, Australia; Brisbane, Australia; and Chester, England!



Perth, Australia
Join the International Walk4PICS
walk4pics.com



Brisbane, Australia
Join the International Walk4PICS
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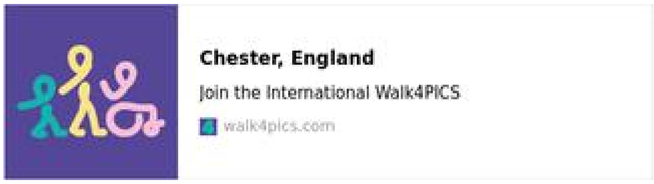

Chester, England
Join the International Walk4PICS
walk4pics.com

Words of Inspiration

In shadows deep, where sorrows dwell,
And wounds of time begin to tell,

A gentle light begins to gleam,
A healing hope, a waking dream.

Though scars may linger, soft and deep,
And memories of pain you keep,

Know that within, a strength resides,
A resilience that gently guides.

With every breath, a new sunrise,
A chance to rise, to reach the skies,

Let go of fear, embrace the grace,
And find your smile upon your face.
For in the healing, you will grow,

A stronger self, a vibrant glow,

And though the journey may be long,
You'll find your peace, your healing song.

Anonymous

Lean Into Hard Things

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