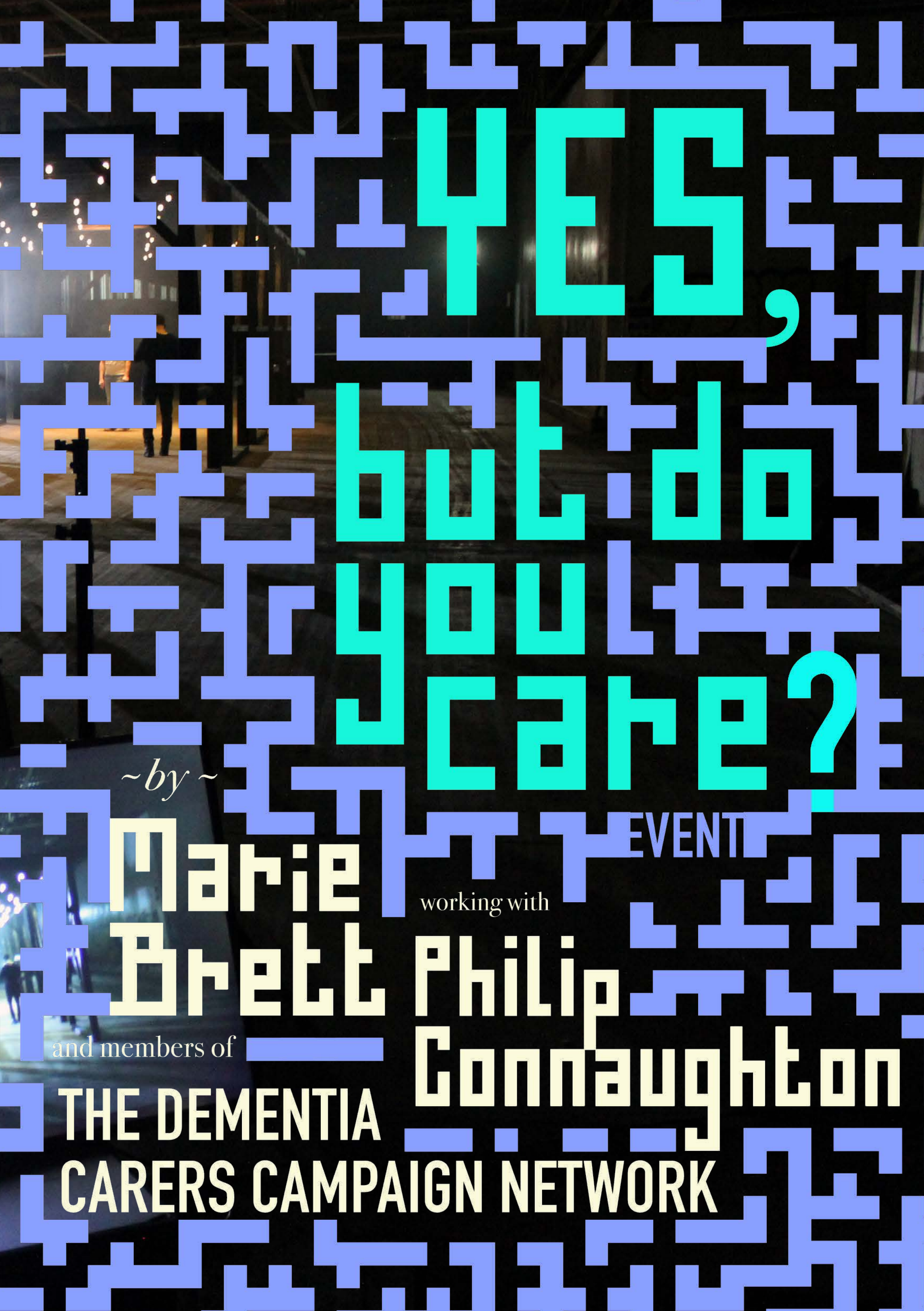

YES, but do you care?

EVENT

~ *by* ~

Marie Brett

working with

Philip Connaughton

and members of

THE DEMENTIA CARERS CAMPAIGN NETWORK

A cross disciplinary, live installation event
Presented with the
IRISH MUSEUM OF MODERN ART
7th – 21st
APRIL
2021

YES, but do you care?

Yes, But Do You Care? (live event) is a cross-disciplinary installation event by visual artist MARIE BRETT working with choreographer/performer PHILIP CONNAUGHTON and members of THE DEMENTIA CARERS CAMPAIGN NETWORK

Yes, But Do You Care? (live event) is part of a body of work exploring the human right to make a bad decision, family care-giving and Ireland’s new capacity legislation and the piece combines live dance and spoken word with floor drawing, sculptural and video elements plus sound and site response.

Materials with metaphoric and symbolic significance were used, including a tonne of salt, timber housing and legislation extracts. The live event and a film documentation were created in 2021 during an Irish governmental level 5 lockdown due to the global COVID-19 pandemic. The work was researched, developed and produced over a two and a half year period spanning 2018 to 2021, and this process included advisor’s inputs from law, arts, advocacy and human rights perspectives.

DYNAMIC KINETIC AFFECTIVE SENSATION

by

Sarah Kelleher

Sarah Kelleher is an arts writer, independent curator and a co-founder of Pluck Projects curatorial team

A man in a white t-shirt stands under the frame of a wooden shelter. He is surrounded by four black clad performers who point their phones at him, lighting him with their torches. He begins to dance on the spot to some internal soundtrack, with exuberance, with something like liberation, until he falls to the floor, exhausted. He appears to be in distress. The people in black follow his descent, crouching alongside as he falls, keeping their lights trained on him.

***

A man enters a warehouse through battered concertina doors. He is bent at the waist, naked except for a pair of shorts and white trainers. Balanced on his back is a sheaf of sticks. The sticks are loose and unwieldy and long, almost as long as he is tall. The man attempts to contain the precarious bundle, his arms reaching backwards. His pose is tightly coiled, as if he is about to dive from a great height. The sticks fall in a tangle around him.

In a cavernous warehouse a man stands in a circle of salt. The salt is deep and neatly raked into two concentric rings, a narrow outer perimeter and wider inner band. He begins to move, his feet planted wide on the clean swept concrete, rolling his head in circles. His movements become more frenetic until, arms outstretched and head thrown back, he spins into the border of salt. As he turns, he kicks up the salt in heavy sprays, and the neat rings blur and scatter.

Yes, But Do You Care? is a work by Marie Brett that considers the Assisted Decision Making Capacity Act, a piece of legislation that supports the facility of people to make decisions about their own resources and personal affairs, free of intervention. The guiding principles of the Act emphasise minimal intervention and due regard to a person’s right to bodily integrity, privacy and autonomy. It supports the human right to make a *'bad'* decision. But it is a complex ethical area to navigate, if for instance the person with the right to make a *'bad decision'* is living with a brain disease such as dementia, and is cared for by a family member, one whose human rights are also implicated.

How can you translate the cold abstraction of a legal document into a visual medium? How do you convey the complexities and nuances of a piece of legislation with far reaching consequences? How do you perform the deep and challenging truths of caring for a person with dementia, without simply representing or exemplifying them? For this work, Brett has collaborated with the dancer and choreographer Philip Connaughton to translate this conceptual and emotional complexity into *'dynamic-kinetic-affective sensation'*. Dance becomes an instrument for organizing meaning and the body becomes the medium through which the hidden truths of lived experience are fleshed out.

Brett′s scenic design provides a framework for unfolding an oblique narrative around the social implications and lived realities of caring.

The work is set in a vast, empty cold storage warehouse which dwarfs Connaughton′s body. Other moments are staged under a wooden structure like a canopy or shelter, its linear framework dramatically lit so that it traps the performers in a grid of shadow. Brett′s practice has previously engaged with the rich significance of folk materials: here, the circle of salt draws a protective cordon around Connaughton, while the sheaf of sticks can be read as both burden, literalising the expression of making a rod for one’s own back, but also as instruments of defence, empowerment or protection.

Connaughton’s choreography produces robust and intense kinetic metaphors for the emotional labour of caring: stop, start, fall and rise, backtrack, breakdown and remake, excitation, stumble and release. Four performers in black function as a chorus, giving voice to first person accounts of caring for someone with dementia, its hardships and tenderness, its moments of absurdity and occasional hilarity. Initially conceived as a live performance, the strictures of Covid meant that Yes, But Do You Care? was re-worked as filmed documentation and so the camera becomes another choreographic element. It whirls alongside Connaughton as he spins inside the salt circle, it transports us to several vantage points within and without the circle of performance. We can linger with the performers’ expressions and gestures, we are granted an intimate proximity with the dancer’s breath and exertion.

In its leveraging of the expressive power of the moving body, Yes, But Do You Care? sits within the recent choreographic turn *(or more precisely ‘return’)* in contemporary performance art, one that is characterised by a very particular use of dance to re-imagine the visual arts through its own procedures and forms. Through the constitutive qualities of dance, such as ephemerality, corporeality and precariousness, choreography can express problems and propose new relationships between bodies, movement, time, sensation and thought. The theorist André Lepicki argues that choreography possess a particular affective-political force within the broader field of contemporary art, because of the ways in which it demonstrates *'an ethics of persisting while facing the demands of absence'*. Dance is necessarily transient, it is a (potentially) endless citation of a singular yet absent choreographic source, a fact which, in Lepicki's words, '*insists on making a dance return: again and again, despite (or rather because of) its ephemerality*'. In this sense, dance might be the art form that best communicates caring as a form of labour - physically demanding, immaterial, self-exploitative and (almost) endlessly repetitive.

Yes, But Do You Care? is both poetic and polemic, animating and enlivening in a cogent way the realities and contradictions of caring and the intensities of its physical and emotional labour. Vitally, Brett and Connaghton position the moving, dancing body as more than an expression of grace and jouissance, but as a persistent, resilient and politicized entity.

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[i] André Lepecki, 'Dance, Choreography and the Visual: Elements for a Contemporary Imagination', in Cosmin Costinaş and Ana Janevski (eds) *Is the Living Body the Last Thing Left Alive?*, (Berlin: Sternberg Press, 2017), pp. 12-19, p. 15

[ii] Between 1958-65 there was a sudden emergence of works by very different visual artists that used dance to re-imagine the ways in which visual art conceived of itself as both a practice and a discourse. Examples would include Allan Kaprow, Robert Morris, Carolee Schneeman and Robert Rauschenberg in the US. Lygia Pape and Helio Oiticica in Brazil, the Gutai Group in Japan and Yves Klein in France. See Lepecki, 'Dance, Choreography and the Visual'

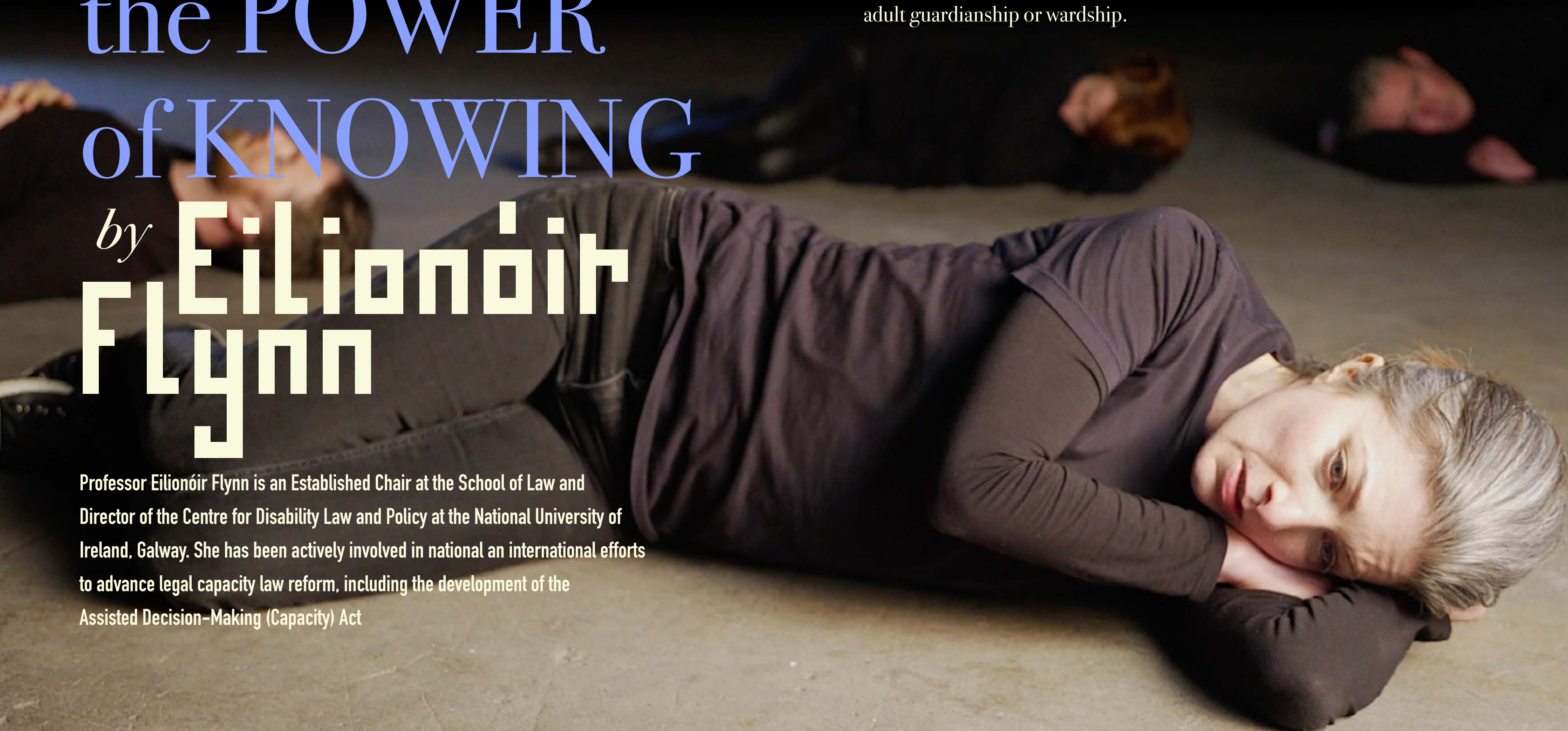
[iii] André Lepecki, '*Dance, Choreography and the Visual*'. 15

[iv] Lepecki, '*Dance, Choreography and the Visual*', 19

The POWER of LAW and the POWER of KNOWING

by Eilionóir Flynn

Professor Eilionóir Flynn is an Established Chair at the School of Law and Director of the Centre for Disability Law and Policy at the National University of Ireland, Galway. She has been actively involved in national an international efforts to advance legal capacity law reform, including the development of the Assisted Decision-Making (Capacity) Act



Legal capacity is the law's way of acknowledging someone as person, and recognising the validity of their decisions in law. We say that legal capacity has two elements – legal standing, and legal agency. Legal standing means being recognised as a person before the law – someone the law has to pay attention to, someone who matters to the law. Legal agency is the power to take actions the law must recognise – to enter a contract, make a will, or get married. Historically, many different groups were denied legal capacity, including women (especially upon marriage), slaves, and racial or ethnic minorities. In contemporary societies, one of the only remaining ways in which adults can be denied their legal capacity is in the form of adult guardianship or wardship.

As a general rule in most legal systems, once you become an adult, your legal capacity is fully recognised and you are entitled to make all legally binding decisions for yourself. You decide what contracts you want to make with others, whether or not to get married, whether to rent a house or take out a mortgage, etc. One of the main exceptions to this is where the law deems an adult to lack mental capacity, to be unable to make a decision for herself. This mostly affects disabled people, including people with intellectual disabilities, people who have experience of mental health services, and people with dementia. When this happens, the law denies legal capacity to that person, either in general, or specifically for a particular decision or set of decisions. New thinking in human rights law seeks to change this approach – to move away from denying legal capacity altogether, and instead, to support people to make decisions for themselves; or in very challenging situations where it is impossible to determine the person's wishes, to do our best to interpret what their wishes would be in that situation, and make the decision on that basis.

The UN Convention on the Rights of Persons with Disabilities is a new human rights treaty that seeks to radically change the way we think about capacity in our law. Article 12 of that Convention makes clear that disabled people, including people with dementia, are entitled to enjoy legal capacity on an equal basis with others, and are entitled to support in exercising their legal capacity. The UN Committee on the Rights of Persons with Disabilities which monitors the Convention at the international level, has provided an authoritative interpretation of how the rights in Article 12 can be implemented in practice in General Comment 1. This General Comment makes clear that states need to abolish systems that discriminate against disabled people by denying their legal capacity, including those that purport to assess the individual's mental capacity, and deny legal capacity accordingly. It demonstrates that when the law makes a decision based on the *'best interests'* of an adult the result can be infantilising and demoralising. While sceptics argue that this radical approach risks abandoning people to dangerous choices, proponents counter that in fact what we are being asked to do is to go deeper, to reach out more, to be more creative and flexible in how we support one another, and recognise the dignity and autonomy of each human being, no matter how complex their disability may be.

In developing these new ideas about how the law can respond to people using support to make decisions, disabled people, and human rights experts, have worked together to demonstrate how flawed our current systems of adult guardianship or wardship are, and how they do not live up to their promise to protect people. Law likes bright distinctions and clear categories; it thrives on the fiction that we can know with certainty who has capacity for a particular decision at a particular moment in time, and who does not. But research, and life experience, shows us that determinations of capacity are far from certain and objective – they are subjective, and value-laden. So much depends on how, when, where and with whom the person's capacity is assessed. Even under the most supportive conditions, experts may disagree as to whether the person actually understands the 'reasonably foreseeable consequences' of their actions. Given this uncertainty, wouldn't it be better to focus not on some arbitrary distinction between having, and lacking capacity, but on understanding what the person actually wants, and trying to respect that wish as much as possible?

Our current law swoops in at a fixed point in time to determine capacity in a way that can dramatically alter the person's future and life choices – and this does not leave much room for grey areas where the person's wishes are unclear, where the person expresses conflicting preferences or where they are clear in their decision initially but subsequently change their mind. By contrast, laws based on a more supportive framework allow new and different possibilities. When we embrace the grey areas and uncertainty, our work to support people is challenging, but more honest, and more rewarding. Those who are sceptical of laws which recognise this supportive approach are concerned that supporters might exploit or take advantage of the person, but there are many ways to prevent this, and we must also acknowledge that the current systems have never succeeded in preventing exploitation.

We all want those we love to be safe and free from harm. Recognising the role of supporters in law can help to keep people safe – because we know from decades and centuries of legal interventions, that it is people who keep people safe, not the law. The more people that know us well, who understand our wishes, who know us through time and understand the choices and mistakes we've made, and continue to love and respect us, the safer we will be. The more supporters that are involved in the process of interpreting a person's wishes, the harder it is for any one individual to dominate the process or exploit the person. We all try to persuade those we love to make decisions we think will be good for them – but this is not the same as the law granting an individual power over another person to make that decision on their behalf, without their consent. That is not persuasion - it is legally sanctioned coercion. And more than that – it's a burdensome legal responsibility, which many people don't even want to have over those they care about in their lives.

Supporting people, not forcing them into decisions, fits more naturally with the ethics of care. But supporters need a safety net too – somewhere to turn for advice and guidance, to make sure they're not letting their impulse to rescue take precedence over their duty to listen, respect and support. Supporters need to be willing to be transparent and accountable, to share how they arrive at interpretations of the person's wishes, but they also need to be trusted by the legal system to do this vital, and delicate work. For too long, the law has regarded only certain kinds of knowledge as objective, trust-worthy or valuable – medical knowledge, and the knowledge of health and social care professionals in particular. But when it comes to the most personal and intimate decisions of our lives – where and with whom to live, who we allow into our home to support us, what we're willing to put our bodies through, how we spend our time – who would you trust to know your wishes and respect your decisions?

For me, the Assisted Decision-Making (Capacity) Act has potential to change how the law tackles these challenging questions, because it grants legal recognition to different kinds of support arrangements, including advance planning mechanisms, that allow people to choose who they want to support them, and when and how this will happen. But this Act is also deeply flawed. It is still based on the fiction that we can be sure about an individual's capacity at a particular moment in time, and grants powers to others to make decisions about our lives, even if we do not want them to, based on a perceived lack of capacity. So we should not be satisfied with this law as it currently stands, but need to push, constantly, for law to continue to evolve, to recognise the complexity of support and decision-making in all of our lives.


-GRUN!

VOICE to VOICELESS, Struggle from within and a relevant catalyst for change

by

Tina Leonard

Tina Leonard is Head of Advocacy and Public Affairs at The Alzheimer Society of Ireland

I'm watching a recording of an online gathering of the Dementia Carers Campaign Network (DCCN) in November 2020, to review the work that was Marie Brett's Yes, But Do You Care? in progress. Members, all existing or former family carers of people living with dementia, open up about what the experience of collaborating on this art project was like. *"When it started in 2019, I was sceptical"* admits Ray Cregan, *"I had thought - we are crying out for services and supports and money is being spent on this. Is it really relevant?"* Other members admit to initial scepticism too. But over the course of the two-year process their views have changed. *"If there is any other way of looking at what we are facing and bringing it to the public, it has to help, it has to make a difference,"* says Susan Crampton, seeing the potential for awareness raising in the work.

Ultimately Ray found the process :
"incredibly cathartic" due to the *"releasing of inner things"*.
"I would encourage more people to be involved in this kind of work,"
he says.

Watching, I'm struck by how powerful a gift it is, to explore and express difficult experiences and emotions and to have those reflected back to you and to others through an artwork. Art can give voice to the voiceless, to the marginalised and the unseen. This is what Marie Brett has achieved with Yes, But Do You Care? Art can be a catalyst for change; change in understanding and then action, within ourselves and then in the wider society.

There are 64,000 people living with dementia in Ireland and many will live with or be supported by family carers. Over 180,000 people in Ireland are currently, or have been, carers for a family member or partner with dementia, with many more providing support and care in other ways. It's a large community of people, and often a hidden one. Yet family carers are providing a crucial service, not only to their loved one but to us all. Over half the total cost of providing dementia care in Ireland is borne by family carers. It is estimated that amounts to €807 million every year.

Family carer stress and ill-health is known, acknowledged and described well in research studies. That family carers are often isolated and under-supported has never been more evident than in the findings of three reports produced and published by The Alzheimer Society of Ireland (The ASI) in 2020-21 on the impact of Covid19 on dementia. "*We're in a permanent lockdown anyway,*" one carer said, as immense stress, burnout and anxiety was reported.

Marie Brett had previously worked with The ASI on E.gress, a filmic art piece exploring ambiguous loss theory in relation to the lived experience of dementia. That work process had involved collaboration with people living with dementia, ASI day centre staff and family carers and it built trust. Marie had toured the film nationally and achieved considerable public engagement.

Then a new piece of legislation came into her view. It became law at the very end of 2015 but is yet to be fully implemented. The Assisted Decision Making (Capacity) Act assumes that decision making capacity exists unless otherwise proven and it outlines assisted decision-making processes. Adopting a rights-based approach is brilliant, not to mention necessary, so that Ireland complies with the United Nations Convention on the Rights of People with Disabilities. It is complex legislation. What impact does the right to make a bad decision have, for example, and what will it mean in practice to the lives of family carers and to their rights? Exploring this is the motivation behind Yes, But Do You Care?

What followed has been a two-year process that is creative, reflective, adaptive, and inclusive. Marie led the initial research phase while she was an invited artist-in-residence at IMMA. Assisted by The ASI, she met DCCN members, dementia specialists at the Mercer Institute for Successful Ageing in St James hospital, scholars at the Global Brain Health Institute at Trinity College Dublin and human rights and law scholars at the National University of Ireland Galway.

In partnership with The ASI, funding was received from the Arts Council via Create, Dublin City Council and Dublin Dance Festival and so began a series of in-person meetings and workshops with DCCN members held in Dublin, Limerick and Cork. These were facilitated by the ASI's Advocacy, Engagement and Participation Officer Laura Reid, who co-ordinates and develops the DCCN's work. Marie distilled all the material from these sessions for dancer and choreographer Philip Connaughton, a partner on the project, to create responses in dance to people's stories and testimony.

Marie worked with a voice coach to choose voiceover actors to read carers' stories.

At this point in time everyone and everything moved online. Initial plans for a live performance event were revised and further funding for this new re-imagined phase was secured from Bank of Ireland and Business to Arts 'Begin Together' programme. In August 2020 a window of lockdown opened and IMMA hosted live public work-in-progress showings in the People's Pavilion. DCCN members kept feeding into the developing work. An advisory team of experts of a variety of disciplines stayed involved. Filming took place at IMMA inside their residential artist's house and grounds while strictly adhering to social distancing guidelines.

And so, while still in lockdown, a live staged installation event was filmed in a large, empty warehouse space. There is live dance and spoken word with projected photographic stills, light, sound and sculptural forms, all directed by Marie. Streamed online for two weeks in April 2021 by both IMMA and The ASI and including online public conversations, the art piece is free to view online and the development of contextual materials is ongoing.

Yes, But Do You Care? is a fearless production and the process of its making gives it immeasurable value. Collaboration and inclusion make it representative and real, and it gives viewers a connection and emotive response that would not otherwise occur. It gives this work power. You will hear, see and feel the challenges of decision making that come with caring through it. Philip Connaughton can quite literally embody an experience or emotion in his dance. DCCN member Máire-Anne Doyle describes Philip's dance as clearly showing "the struggle from within". "The demon guilt can suffocate you," she says describing how the responsibility and the guilt of decision making can be overwhelming.

"You're screaming inside permanently. Philip's movement really does link with the words we expressed."

This is art linking the private to the public. Reimagining Yes, But Do You Care? to be presented online will mean a new and wider audience can be found now and in the future. There are so many ways to connect with this piece and so there is surely an audience beyond the traditional art audience. Family carers can find in it a reflection of their own emotions and may experience catharsis themselves in turn as DCCN members did. Health practitioners, human rights lawyers, researchers and advocates will all find something here that impacts positively on their work and at the very least enriches it by providing a different perspective to the one they are most familiar with.

"I was keeping down emotions that were perfectly normal, but nobody spoke about them," Máire-Anne Doyle of the DCCN said. Yes, But Do You Care? brings these emotions out of the shadows. The Alzheimer Society of Ireland is proud to have played a role in this work and congratulates Marie Brett on her achievement and on her tenacity in keeping the work going through so much societal upheaval.

YES, BUT DO YOU CARE?

BACKGROUND

Artists Marie Brett and Philip Connaughton have each made considerably accomplished earlier works which compellingly explore relation to some of life's more complex issues. Visual artist Brett has special interest to human experiences recurrently involving trauma, stigma and social (in)justice, and first met choreographer/performer Connaughton when she was exhibiting and touring *E.gress*, and invited Connaughton to create a dance response to the piece. *E.gress* is a filmic work which explores how ambiguous loss theory relates to a lived experience of dementia and Brett made this piece in collaboration with musician Kevin O'Shanahan and people living with a dementia, in partnership with The Alzheimer Society of Ireland. This work is now in the Arts Council | An Chomhairle Ealaíon national collection.

A period of time later, Brett was an invited artist in residence at the Irish Museum of Modern Art (IMMA) and researching the impact of family caring for a person with a dementia brain disease. She attended a Law Society human rights event which questioned the complexity of Ireland's new capacity legislation and its relation to family care giving. Brett was curious and pursued further research which led to her inviting members of the Dementia Carers Campaign Network and performer Connaughton into a process of collaboration, so as to creatively explore some of these complexities. As their project progressed; advisors in law, arts and human rights also folded into the process.

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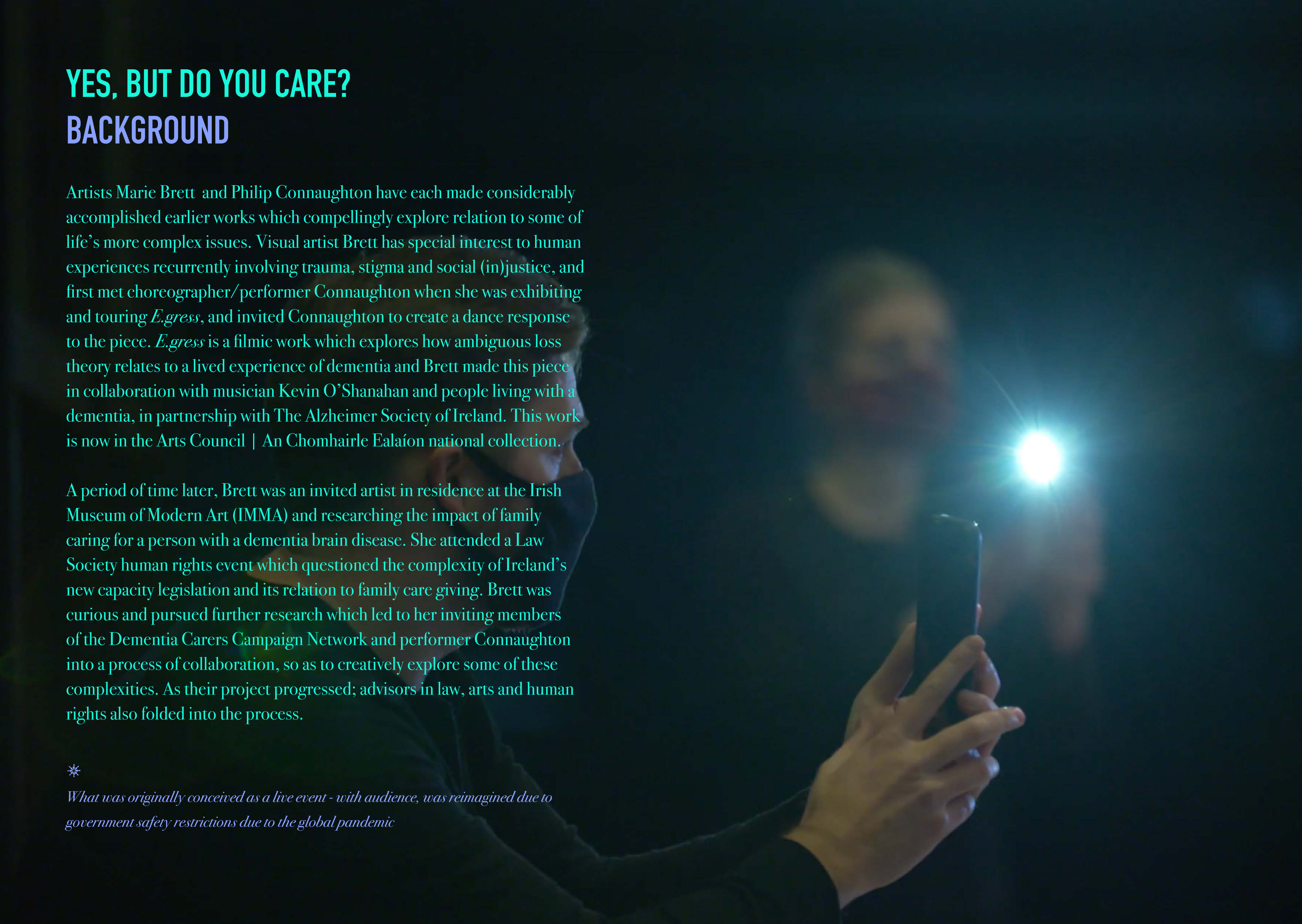
What was originally conceived as a live event - with audience, was reimagined due to government safety restrictions due to the global pandemic



Marie Brett

Marie Brett is a visual artist working across filmic, immersive sculptural installation and more recently live event, making work about profound human experiences recurrently involving trauma or social (in)justice. Regarded by many as a leading exponent of trans-disciplinary social arts practice, resulting artwork is located in both gallery settings and unusual off-site venues. Brett graduated from Goldsmiths, London University, with MA (distinction) and BA (1st class) degrees. She has artwork held in national and international arts collections and writings published in Ireland, the UK and Finland. Recent work includes an international global justice commission and exhibition at Brussel's European Parliament; a live underground event in an ex-military coastal fort; and being lead-artist with Cork Midsummer Festival developing a work about trafficking and modern-day-slavery aligned to a ten country platform.

Philip Connaughton

Philip Connaughton is a choreographer/performer from Dublin. He trained at the Rambert School of Ballet and Contemporary Dance in London. He was artist in residence at axis:Ballymun in 2012 and associate artist of Dance Ireland in 2013 and in 2014, he formed Company Philip Connaughton. His body of work to date includes, Mortuus Est Philippus; Tardigrade; Whack!!- in collaboration with Compagnie Kashyl; Extraterrestrial Events; Assisted Solo; Mamafesta Memorialising. He has also worked extensively on various productions in theatre and Opera. He is currently working on developing a new work with Phillip McMahon for THISISPOPBABY. He is a Project Arts Centre resident artist and an associate artist of THISISPOPBABY.

THE DEMENTIA CARERS CAMPAIGN NETWORK

The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of Ireland, are an advocacy group for those who have experience caring for a loved one with dementia. They aim to be a voice of, and for, dementia carers in Ireland and to raise awareness of issues affecting families living with dementia. Since the group was set up in 2013, they have participated in research programmes on dementia and the needs of family carers, spoken at conferences and events across Ireland, been involved in monitoring the implementation of Ireland's first National Dementia Strategy, provided feedback on Alzheimer Society of Ireland policy documents and campaigns and met with political representatives to campaign for policy change plus taken part in awareness raising activities, including national and local media work.

Dementia Carers Campaign Network contributors:

Tony Browne
Declan Cassidy
Susan Crampton
Raymond Cregan
Daisy
Richard Dolan
Máire-Anne Doyle
Martin Joseph Dunn
Breshan Evans
Brigid Forde
Joan Heaney
Helen Higgins
Theresa McMahon
Marie O'Brien
Nuala O'Connell
Daniel O'Donovan
Donna O'Donovan
Sinead O Rahilly
Helena Quaid
Sean Quinlan
Laura Reid
Chloe Shine
Paula Tangney
Judy Williams
Maria Willis

LIVE EVENT / PERFORMERS

Dance :
Philip Connaughton
Spoken Word :
Eugene D'Arcy
Collette Forde
Claire Loy
Michael Sands
Salt Drawing:
Nic Piper & Marie Brett

Written Passages :
Marie Brett
Filming :
Epic Productions
Photography :
Marie Brett

YES, but do you care?

LIVE INSTALLATION EVENT
by visual artist **MARIE BRETT**
working with
choreographer/performer
PHILIP CONNAUGHTON
and members of the
DEMENTIA CARERS CAMPAIGN NETWORK

ADVISORS / ASSISTED BY:

The Alzheimer Society of Ireland :
Vanessa Bradbury
Cormac Cahill
Avril Easton
Tina Leonard
Laura O'Philbin
Clodagh Whelan
Studio Space :
Axis Ballymun
Dementia Carers Campaign Network,
Coordinators :
Laura Reid
Judy Williams
Felton McKnight Solicitors :
Mark Felton
Trinity College Dublin, Global Brain Health Institute :
Dr Francesca Farina

IMMA :
Bairbre-Ann Harkin
Janice Hough
Helen O'Donoghue
Poetry Ireland :
Jane O Hanlon
Voice / drama development :
Andrea Ainsworth
Martin Drury
Sharon Murphy
Clodagh Piper
Written response :
Dr Eilionóir Flynn
Sarah Kelleher
Tina Leonard
Graphic Design :
Lucia Pola

Supported by The Alzheimer Society of Ireland

** Created in level 5 lockdown in Ireland during the COVID-19 pandemic*

www.yesbutdoyoucare.ie

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funding the arts
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create
create national development agency for collaborative arts
Bank of Ireland
Begin Together ARTS FUND
Business to Arts Developing Creative Partnerships
Comhairle Cathrach Bhaile Átha Cliath Dublin City Council
Dublin Dance Festival
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IMMA 30