



QUEEN'S
UNIVERSITY
BELFAST

DEMENTIA FICTION FESTIVAL

15TH-16TH SEPTEMBER 2021

WELCOME

DEMENTIA FICTION FESTIVAL

15TH-16TH SEPTEMBER 2021



Dementia is one of the most significant illnesses of our time, with 50 million people living with the condition and many more whose lives are affected. In the absence of a cure, the onus is on us as a society to better understand and respond to the challenge. Writers are playing their part by creating characters who have dementia, giving readers insight into the condition.

The Dementia Fiction Festival celebrates the wealth of new fiction depicting dementia, exploring the issues raised around ethics, diversity, empathy and care. As well as performances of new writing, the festival features a series of workshops, panel discussions and keynote talks from researchers, creative writers, and people living and working with dementia.

The Dementia Fiction Festival is the culmination of an AHRC-funded research project being carried out by a team of researchers at Queen's University Belfast, who are investigating the potential for fiction to promote awareness and understanding around the lived experience of dementia.

All are welcome.

“The
Dementia
Fiction
Festival
celebrates
the wealth
of new
fiction
depicting
dementia”

DAY 1

WEDNESDAY 15TH SEPTEMBER 2021

09:45

ONLINE WELCOME AND ORIENTATION WITH JAN CARSON

10:00 - 11:00

KEYNOTE ONE DEMENTIA IN THE MINDS OF CHARACTERS AND READERS Dr Jane Lugea (QUB)

This talk reports on the research behind the festival, a project carried out by a team of researchers at Queen's University Belfast and led by Dr Jane Lugea. Inspired by the recent boom in fiction depicting characters with dementia, Dr Lugea explores how these texts represent their subjective experience and the tricks of language that enable readers to simulate that experience. Through a series of reading groups using extracts from the fiction, the team are investigating the possibility for fiction to facilitate awareness of and empathy towards those living with the condition. The talk will share preliminary findings of the reading group research and explore the power of fiction to contribute to our understanding of dementia.

11:30 - 12:30

PANEL ONE RESEARCH FINDINGS

Dr Jane Lugea (QUB) will lead this interactive conversation as writers and academics discuss and respond to the findings of the 'dementia in the minds of characters and readers' research project as outlined in the previous keynote. The session will feature contributions from **Prof Tess Maginess** (QUB), **Dr Chloe Harrison** (Aston University) and **Dr Naomi Krüger** (University of Central Lancashire) who will read from her recent novel *May* (2018, Seren Books).

13:30 - 14:30

PANEL TWO THE ETHICS OF WRITING DEMENTIA

Dr Gemma Carney (QUB) will moderate this interactive discussion on the ethics of how we write about dementia. Exploring issues such as dignity, research and appropriation the panel will ask some important questions in regards to how writers can ethically write and record another's experience. The panel will feature a presentation from **Dr Sarah Falcus** (University of Huddersfield), alongside input from writer and academic **Caleb Klaces** (York St John University) **Peter Middleton** who is living with Alzheimer's and Dublin-based novelist **Henrietta McKervey** who will read from her 2016 novel *The Heart of Everything* (Hachette, 2016).

15:00 - 16:00

PANEL THREE DIVERSITY IN DEMENTIA NARRATIVES

Writer, **Jan Carson** will chair this lively panel on issues around diversity in dementia narratives. Raising important questions around a seeming lack of diverse representations in the portrayal of dementia, this conversation will also explores ways in which we can foster more diversity in writing and thinking about dementia. The panel will begin with a short talk from **Dr Bas Groes** (University of Wolverhampton), on diversity within literary and on screen representation of dementia, a reading from Irish poet **Rachael Hegarty** whose most recent work explores her mother's experience of dementia and contributions from **Bindi Dhesi** (Alzheimer's Society).

16:15 - 17:15

COCKTAIL HOUR A SERIES OF FACILITATED CONVERSATIONS

Grab a drink and join the members of the dementia fiction research team for a series of online chats about various topics related to the project and festival. Break-out rooms will be dedicated to specific topics so that you can get to know other people with similar interests. Feel free to ask questions, swap information and make new contacts. You don't have to be an expert to join the conversation. Everyone is very welcome. We can't invite you to an in-person drink at the bar, but we hope this will be the next best thing.

19:00 - 20:30

PERFORMANCE AND DISCUSSION DEMENTIA AND THEATRE

Over the last number of years Northern Irish theatre company, *Prime Cut* have consistently delivered cutting edge, high quality plays and theatre projects which explore some of the most pressing societal issues of our time. In this performance and discussion, **Vittoria Caffola** (*Paradosso Theatre*), will introduce and chat to executive producer **Una NicEoin** and playwright **Caoileann Curry-Thompson** about *Prime Cut*'s history of engaging with dementia. The panel will include recordings of previous productions and an excerpt from Curry-Thompson's new play which explores her father's dementia experience. The panel will conclude with an opportunity for the audience to ask questions and contribute to the discussion.

DAY 2

THURSDAY 16TH SEPTEMBER 2021

09:45

ONLINE WELCOME AND ORIENTATION WITH JAN CARSON

10:00 - 11:00

KEYNOTE TWO FROM TABOO TO TOPICAL: THE POWER OF PORTRAYALS OF DEMENTIA Prof Jan Oyeboode (University of Bradford)

Dementia has emerged from being taboo to being topical. The way it is portrayed has real-life implications for how people with dementia feel about being diagnosed and living with the condition; it influences the attitudes and actions of those of us without dementia towards people with dementia; it impacts on the value society places on the lives of those with a diagnosis. In this talk, I will highlight some common portrayals of people with dementia, drawing on fictional as well as personal accounts. I shall try to show how different perspectives produce different ripples, that can undermine or support, educate or misinform, and connect or divide us.

11:30 - 12:30

PANEL FOUR WRITING NON-FICTION, MEMOIR AND BIOGRAPHY

Anna Wharton, novelist and recent ghostwriter of Wendy Mitchell's bestselling memoir, *Somebody I Used to Know*, chairs this fantastic conversation about writing non-fiction accounts of dementia. The panel will also feature a short presentation by **Dr Lucy Burke** (Manchester Metropolitan University), Irish writer, **Ian Maleney** whose essay collection *Minor Monuments* (Tramp Press, 2019), explored how his grandfather's Alzheimer's diagnosis impacted his extended family and **Sue Leonard** who has recently co-written *If Memory Serves Me Well* (New Island, 2021) with former actor and Riverdance manager, **Ronan Smyth**. Ronan will contribute a pre-recorded message to this discussion.

13:15 - 14:15

PANEL FIVE DEMENTIA NARRATIVES IN CHILDREN'S AND YA LITERATURE

We're delighted to include a conversation about how dementia can and should be explored in books aimed at children and young adults. **Elaina Ryan** of Children's Books Ireland will chair this important and engaging conversation with celebrated Irish novelist, **Sarah Moore Fitzgerald**, who will read from her debut novel *Back to Blackbrick* (Simon and Schuster, 2013). **Non Pratt**, YA novelist and

member of the team at Walker Books will represent the publishing world, while **Dr Amanda Piesse** will also bring years of experience as a former academic specialising in the representation of ageing in children's literature, alongside personal experience working in the voluntary and community arts sector.

14:30 - 15:30

PANEL SIX READING AND WRITING IN THE COMMUNITY

Our final panel, chaired by English poet and community arts facilitator **Dr Sarah Hesketh**, will take a brief look at some of the best and most innovative arts projects which engage people living with dementia, their friends, family and carers in reading, writing and theatre. **Prof Kate de Medeiros** (Miami University) will begin this session with a short talk on the opportunities and benefits afforded by community arts projects. **Susanna Howard** of *Living Words* and **Sinead Devine** of *DEEDS* will share from their own extensive experience in this area. Exploring both the importance of arts engagement and practical ways to get involved in such projects, this panel promises to be a really inspiring one.

16:00 - 16:30

ONE TO ONE CHAT

Grab a cuppa and join writer, **Jan Carson** and Dementia NI member, **Davie McElhinney** for an informal and engaging conversation about what it's like to live with dementia. Davie will give us an insight into his diagnosis, his everyday life and the community he's found at *Dementia NI*. Jan will raise some important questions about how writers should approach writing about dementia. This chat will be honest, useful and an absolutely essential watch for any writer thinking about exploring dementia in their work.

19:00 - 20:30

GALA READING AND DISCUSSION

Writers have been at the heart of our research project and we want to conclude our dementia fiction festival with a celebration of some of the best dementia narratives we've come across in the last few years. **Marjorie Lotfi** (*Open Book*), will be our host for the evening as she introduces two poets, **Sarah Hesketh** and **Lynda Tavakoli**, and two prose writers, **Anna Wharton** and **Niamh Mac Cabe** whose writing approaches the subject of dementia in innovative, imaginative and informative ways. The session will include both a reading by the four writers and a brief chat about their process, the development of their work and their ongoing interest in dementia.

FESTIVAL CONTRIBUTORS



LUCY BURKE

Dr Lucy Burke works in the Faculty of Arts and Humanities at Manchester Metropolitan University and published widely in the field of literary and cultural dementia studies. She is on the editorial board of the Journal of Literary & Cultural Disability Studies & an associate fellow of the Centre for Ethics in Medicine and Society at Monash University.



VITTORIA CAFOLLA

Vittoria is a playwright based in Belfast. She is currently under commission to the Lyric Theatre Belfast and is one half of Paradosso Theatre Company. She has written for Kabosh, Fishamble, Agent160 Theatre Company. Abooo, Big Telly amongst others and has had her work performed all over the UK & Ireland. She holds a MFA in playwriting from The Lir, Trinity College, Dublin.



GEMMA CARNEY

Dr. Gemma Carney is a social gerontologist and senior lecturer in social policy at Queen's University Belfast. Gemma has been researching ageing and later life since her first job as Policy Analyst at the Irish Senior Citizen's Parliament in 2007. Since then, she has been working on or leading a range of projects on ageing, often with artists, writers or humanities scholars such as [The Lively Project](#). She is active in British gerontology serving on various committees which promote the study of ageing. Her book *Critical Questions for Ageing Societies* (with Paul Nash, University of Southern California) offers a thought-provoking introduction to longevity and was nominated for the Richard Kalish award by Gerontological Society of America in 2021. She is Co-Investigator on the Dementia in the Minds of Characters and Readers project.



JAN CARSON

Jan Carson is the Belfast based author of two short story collections, two novels and two micro-fiction collections. Her novel, *The Fire Starters* won the EU Prize for Literature for Ireland in 2019. Her next novel, *The Raptures* will be published by Doubleday in Spring 2022. Jan has worked in community arts facilitation for the last twenty years.



CAOILEANN CURRY-THOMPSON

Caoileann Curry-Thompson is a playwright and theatre-maker based in Belfast. Alongside her practice, she has worked in research, and has a PhD in performativity and theatricality in the plays of Stewart Parker, from QUB. She is currently Acting Head of Drama with the Arts Council of Northern Ireland. She recently lost her dad who had been living with dementia.



KATE DE MADEIROS

Kate de Medeiros is the O'Toole Professor of Gerontology at Miami University, Oxford, Ohio. Her research on dementia has included friendships among people living with dementia; risk and creativity in long-term care settings; flourishing in later life; and dementia in a global context.



SINEAD DEVINE

Sinead Devine has worked in community arts practice for over thirty years, establishing an award-winning community arts department for Derry Playhouse from its inception in 1992. She moved to the Old Library Trust in 2018 as a Support Worker for DEEDS (Dementia Engaged and Empowered Derry & Strabane) where she developed arts and other activities for those living with early-stage dementia. She took over as Co-ordinator for DEEDS in 2020 and part of the role is to continue to develop links and opportunities for those living with dementia to access connections in the community e. g. dementia friendly cinema days, performances and creating links to arts organisations and venues. She is very passionate about developing and presenting the stories of people in the community through a wide variety of medium.



BINDI DHESI

Bindi Dhesi is Dementia Voice Lead for Alzheimer's Society, covering North East, Yorkshire and Lincolnshire. Bindi has been with Alzheimer's Society for 11 years and has a passion for listening to the voice of people with lived experiences of dementia. Bindi has been involved in a project around creating a resource around enabling conversations around future planning (Advance Care Planning). This was a coproduction with people affected by dementia and

Alzheimer's Society Local Services. In her spare time Bindi enjoys walks around her local area and testing out quick food/ recipe cooking hacks.



SARAH FALCUS

Sarah Falcus is a Reader in Contemporary Literature at the University of Huddersfield. She has research interests in literary and cultural gerontology, science and speculative fiction, and children's literature. She is the co-author, with Katsura

Sako, of *Contemporary Narratives of Dementia: Ethics, Ageing, Politics* (Routledge, 2019).



BAS GROES

Bas Groes is Professor of English Literature at the University of Wolverhampton where he leads the Arts and Humanities Research Council-funded *Novel Perceptions: towards an inclusive canon*.

He led The Memory Network,

edited the ground-breaking book *Memory in the Twenty-First Century* and recently completed his stroke memoir, *Right in the Head*.



CHLOE HARRISON

Dr Chloe Harrison is Senior Lecturer in English Language and Literature at Aston University. Her research interests include cognitive stylistics (and specifically the application of Cognitive Grammar for literary-linguistic

analysis), re-reading and contemporary fiction. She has a number of publications in these areas, including: *Cognitive Grammar in Contemporary Fiction* (Benjamins 2017) and *Cognitive Grammar in Stylistics: A Practical Guide* (with Marcello Giovanelli, Bloomsbury 2018) and *New Directions in Cognitive Grammar and Style* (with Marcello Giovanelli and Louise Nuttall, Bloomsbury 2021). She is also Treasurer for the International Association of Literary Semantics.



RACHAEL HEGARTY

Rachael Hegarty's debut collection, *Flight Paths Over Finglas* won the 2018 Shine Strong Award. A child survivor of the Talbot Street bomb, her collection *May Day 1974* (Salmon, 2019) has received international critical

acclaim. Her third collection, *Dancing with Memory* (Salmon, 2021) is a dance hall of memory for her mother who lives with Alzheimer's.



SARAH HESKETH

Sarah Hesketh is a writer and editor. In 2013 she was poet-in-residence with Age Concern, working with elderly people with dementia, and in 2014 she published *The Hard Word Box* (Penned in the Margins), a collection of poems and

interviews inspired by this experience. She is the editor of The Emma Press anthology of Poems about Age. She currently lives in London and works as Managing Editor for Modern Poetry in Translation magazine.



SUSANNA HOWARD

Susanna Howard is the founder and artistic director of Living Words, an arts and literature charity which works with people experiencing dementia and isolated people and recently worked on 'Bringing the Inside Out,' a publication of

the words of people living in, working in, and visiting care homes during the pandemic. Susanna is the co-curator of 'Normal? Festival of the Brain' in Folkestone and part of the 'Created Out of Mind' team at the Wellcome Hub.



CALEB KLACES

ior Lecturer in Creative Writing and English Literature at York St John University. His first poetry collection, *Bottled Air* (Eyewear, 2013), won the Melita Hume Prize and an Eric Gregory Award from the Society of Authors. His novel,

Fatherhood, was published by Prototype in 2019. Caleb has a BA from Oxford University and an MA from The University of Texas. He is currently working on a novel about his father's dementia experience.



NAOMI KRÜGER

Naomi Krüger lectures in Creative Writing at the University of Central Lancashire. Her debut novel, *May*, was published in 2018 by Seren and her short fiction has been published in various literary journals. She has an

MA and PhD from Lancaster University and was recently awarded an Eccles Centre Fellowship to research her second novel at the British Library.



SUE LEONARD

A Journalist and Ghostwriter, Sue Leonard co-wrote *If Memory Serves Me Wrong*, with the former actor and Riverdance manager, Ronan Smith. (New Island Books.) She has co-written 11 other books, two of them number

one bestsellers. A prolific arts journalist, Sue writes the Beginners Pluck Book column for the *Irish Examiner*. Born in Oxford, She lives in County Wicklow.



MARJORIE LOTFI

Marjorie Lotfi is a Co-Founder and the Development Director of Open Book, a charity running shared reading and creative writing workshops in community settings across Scotland. She is also the Chair of the Board of Trustees for

the Wigtown Book Festival and on the Board of StAnza, Scotland's Poetry Festival. As a writer, Marjorie's poetry has won competitions, been published widely in the UK and abroad and performed on BBC Radio 4. *Refuge*, poems about her childhood in revolutionary Iran, is published by Tapsalteerie Press.



JANE LUGEA

Dr Jane Lugea is Senior Lecturer in English Language at Queen's University Belfast. She specialises in the language of literature, particularly in how stylistic choices made by authors lead to cognitive effects in readers. She is leading

an AHRC-funded research project, *Dementia in the Minds of Characters and Readers*, which explores how dementia is represented in the minds of fictional characters, and how readers respond to those characters.



TESS MAGINESS

Tess Maginess is Professor of Lifelong Learning in Queen's University Belfast, where much of her work is in adult education. She teaches literature. Tess obtained her BA from Trinity College, Dublin, her MA from Queen's University

and her PhD from York University, Toronto. She has published several books and articles and a book of poems.



IAN MALENEY

Ian Maleney is a writer living in Dublin. His first book, a collection of essays entitled *Minor Monuments*, was published by Tramp Press in 2019. He is the editor at Fallow Media.



NIAMH MAC CABBÉ

Niamh Mac Cabe is a Leitrim-based visual artist and award-winning writer, published in many journals and anthologies including *The Stinging Fly*, *Narrative Magazine*, *Mslexia*, No Alibis Press' *Still Worlds* Turning, Southword, The Irish

Independent, Wasafiri, The London Magazine, *Aesthetica*, *Structo*, The Lighthouse, *tears-in-the-fence*, *Bare Fiction*, The Lonely Crowd, *Retreat West*, and The Bristol Prize Anthology.



DAVIE MCELHINNEY

Davie was diagnosed with Fronto-temporal dementia at the age of 54. Originally a chef, his life changed dramatically with his diagnosis. Being involved with Dementia NI has really helped him grow in confidence and given him a

voice. Having met loads of the most incredible people on his journey, he has clearly seen that there is a full life after the diagnosis. Davie is very proud to sit on the board of Dementia NI and help to shape the future of the charity and to try and help and to support people when they receive the shocking dementia diagnosis.



HENRIETTA MCKERVEY

Henrietta McKervey has published four acclaimed novels: *The Heart of Everything*, an Irish Times bookclub choice, which explores the impact of dementia and loss on a family; *A Talented Man*; *Violet Hill*; and *What Becomes Of Us*. She won

a Hennessy Award and the inaugural UCD Maeve Binchy Travel Award. Born in Belfast, she now lives in Dublin.



PETER MIDDLETON

Peter was born in 1954 and grew up in Clapham, South London. He married Pam in 1975 and joined the Royal Air Force (RAF) in 1976, spending the next 18 years working at home and abroad as an aircraft technician. On leaving

the RAF, Peter began a career as a technical author and Senior Consultant in Information Systems. For the last 10 years before his retirement, he worked as a Police Community Support Officer. His hobbies include software testing, reading, a love of facts and learning, he enjoys the countryside and walks for relaxation. Peter develops simple phone apps as a hobby and is a blogger. He has 2 daughters and 6 grandchildren. He has Alzheimer's disease. He is living with dementia.

relationships in dementia, and how the impact of dementia, and ways of coping with it, are influenced by diversity, including culture, type of dementia, and age of onset.



AMANDA PIESSE

Amanda Piesse lectured in English Literature at Trinity College Dublin from 1991-2017. Her special interests include early modern literature and children's literature, especially the representation of older people in both literatures. She

currently lives on the Ards peninsula, volunteering for the Time to Read project and the NSPCC Young Witness Support Programme and doing the odd bit of consultancy with various writing and theatre projects.

well as in the arts, and later became an advocate for the Alzheimer Society of Ireland and a founding member of the Irish Dementia Working Group. Ronan lives in Lacken, County Wicklow, with his wife Miriam and their two children, Hannah and Loughlin.



LYNDA TAVAKOLI

Lynda Tavakoli has written widely about the subject of aging and its effect upon her family. Her dementia-related poetry and prose have featured in The Irish Times and broadcast on BBC Radio Ulster and RTE. Her

debut poetry collection *The Boiling Point for Jam* contains poems that she hopes will offer insight into dementia and its many personal challenges.



SARAH MOORE FITZGERALD

Sarah Moore Fitzgerald is an award winning teacher and researcher based at the University of Limerick. Since becoming a published novelist almost ten years ago, she's been shortlisted for many literary awards including the

Waterstones Prize, The Irish Book Awards, The Jack Harte Bursary and the Calderdale Prize. Her sixth novel *All The Money In The World* came out in July. Though a work of fiction, Sarah's debut novel, *Back to Blackbrick* (2013) draws on her personal experience of losing her beloved Dad to dementia.



NON PRATT

Non Pratt is the critically acclaimed author of *Trouble*, *Remix*, *Truth or Dare* and *Every Little Piece of My Heart* YA novels published by Walker Books, and *Unboxed* and *Second Best Friend*, novellas published by Barrington Stoke. Non

has also collaborated with six other UK authors to create *Floored* and adapted John Allison's hit comic series *Giant Days* into a novel. All her/their novels feature teenagers getting up to all the things Non wanted to do at that age (but didn't), dealing with issues such as teen pregnancy, friendship and social media with a light touch and a lot of realism. Now a Senior Editor at Walker Books, Non still writes a little bit when the mood strikes.



ANNA WHARTON

Anna Wharton has been a print and broadcast journalist for more than 20 years, writing for newspapers including *The Times*, *The Guardian*, *The Sunday Times Magazine*, *Grazia* and *Red*. She was formally an executive editor at the *Daily Mail*. She has

also ghostwritten five memoirs including the Sunday Times bestseller, *Somebody I Used to Know* by Wendy Mitchell, and the Orwell Prize longlisted, *CUT: One Woman's Fight Against FGM in Britain Today* by Hibo Wardere. She received an MA in Creative Writing from the University of East Anglia and her debut novel, *The Imposter*, was published in April 2021. Anna and Wendy's second book *What I Wish People Knew About Dementia* will be published in January 2022.



UNA NICEOIN

Una NicEoin became Executive Producer at Prime Cut Productions in 2009. Since then she has produced 21 shows for the company including *Red* and internationally touring shows *Removed*, *Hard To Be Soft* and *Scorch*. Una has delivered

presentations at a variety of conferences and events for Creative Europe, Queens University, NUI Galway, British Council, Arts Council NI, Theatre NI/Theatre Forum, IETM and IPAY. Una was Chair of Ponydance Dance Company until 2021 and an Artistic Associate of Streetwise Community Circus.



ELAINA RYAN

Elaina Ryan is CEO of Children's Books Ireland, a non-profit organisation whose mission is to inspire a lifelong love of reading in children and young people in Ireland. Children's Books Ireland champions every child's right

to excellent books, shares expertise and enthusiasm with adults who influence children's reading and supports authors and illustrators who make work for children.



JAN OYEBODE

Jan Oyeboode is Professor of Dementia Care, Centre for Applied Dementia Studies, University of Bradford. She has spent much of her career in the NHS, as a clinical psychologist with older people. Her research interests focus on family



RONAN SMITH

Ronan Smith has had a distinguished career as an actor, director and producer, working in most of the major theatres in Dublin and with many of Ireland's leading companies on projects big and small, from The Gaiety Theatre pantomime to

the iconic *Riverdance*. He has served in a voluntary capacity on many boards in the fields of education and health as



You can follow festival updates on Twitter @fictiondementia and Tweet along with the festival using the hashtag #DementiaFictionFest21



Most sessions will be available to watch after the festival on our YouTube channel – Dementia Fiction



If you have any questions or comments, feel free to contact the lead researcher
on the 'Dementia in the minds of characters and readers' project,
Dr Jane Lugea: j.lugea@qub.ac.uk

<https://blogs.qub.ac.uk/dementiafiction/>

