AGENDA

British Geriatrics Society
Improving healthcare for older people

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Person centred care

Putting older people's priorities first

PLUS

- **Front door frailty**
- Older people in research
- **BGS Autumn Meeting 2023**

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AGENDA
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On the AGENDA

President's *Message*

A new year. New beginnings. January, Wikipedia tells me, was named after the Roman god Janus. Famously two-faced, but actually the god of new beginnings, passages, transitions and change.

So which might a New Year bring for those of us working in care of older people? By the time you read this we will no doubt have battled through Christmas and New Year. If you're reading it, then at least some of us survived. The omens suggest it will be difficult and at least as bad as last year – and that was the worst on record. In addition, we will have supported doctors in training, and looked after our patients, through the longest doctors' strike in NHS history.

And that's just the beginning. We'll face continued pressures and uncertainties. In England we have a long-term workforce plan, but little concrete idea about how it will be operationalised. Some solutions proposed therein are subject to considerable challenge, not least the role of Physician Associates and Medical Apprenticeships.

We'll face continued high service demands, driven partly by population ageing and medical complexity, and partly by chronic underfunding that means services cannot rise to meet the challenge. In parts of the system, service designs persist which are insufficiently cognisant of frailty. There remains no sustainable solution on the table for social care in England, Northern Ireland or Wales. In Scotland, the National Care Service exists in concept only. We know that underdeveloped and under-resourced social care services lie at the heart of many of the problems our patients face – and drive at least some of the failure demand we see across the NHS. Strikes are likely to continue.

So change, but *plus ça change*? Maybe not. Hope lies in the way that the frailty narrative has been embraced during 2023 in a way not seen hitherto. Frailty and evidence-based approaches to caring for people who live with frailty featured this year in the Urgent and Emergency Care Recovery Plan, the NHS England Long-Term Workforce plan, and the Chief Medical Officer's Annual Report. It drove novel policies around hospital at home, and increased focus on front-door frailty services. A national framework for rehabilitation, reablement and recovery was published by NHS England. And as I write this piece, NHS England have released their long-awaited Proactive Care guidance. Whilst there's a lot of uncertainty about how this will play out on the ground, its uplifting to see guidance that reinforces the need to move form reactive to proactive approaches in frailty care.

> 'I was inspired at a recent meeting when the President of the Royal College of Emergency Medicine, sat next to me, said that he'd never seen a service that wasn't improved by the involvement of the BGS membership.'

Some of these areas of progress have generated problems of their own. It is ever thus. There are also areas where the national narrative was not as good as we could have hoped for. The Major Conditions Strategy at its first publication by the Department of Health and Social Care failed to mention frailty – something that we've made representations about. More concerning still is what we've seen from the UK COVID-19 Inquiry. BGS had not planned to comment on this until its conclusion – but our members have been so moved by the many exemplars of structural ageism contained therein that we issued a statement now. We have printed the statement in full in this issue of *AGENDA* - turn to page 11 for more information.

Some change is guaranteed in 2024. The announcement of a general election is a constitutional inevitability. Any government is likely to be bound by the spending plans of the current incumbents for the early part of their administration. Care of older people will be one of many competing priorities in a resource-constrained system and we'll have to make our case well.

During 2023, the BGS team made appearances at both the Labour and Conservative Party conferences. We continue to actively engage with both the current government and current opposition to do everything we can to hold care for older people within the narrative. We will intensify these efforts as we move towards a general election and we will work with partners in the third sector as we do so. Time is of the essence – general elections come with a period of purdah which makes policy progress impossible… and things take a bit of things to settle afterwards.

So what can we do on the ground? I was inspired at a recent meeting when the President of the Royal College of Emergency Medicine, sat next to me, said that he'd never seen a service that wasn't improved by the involvement of the BGS membership. There's something in that. We know, for the most part, where we add value – if we keep doing what we do, where we know it works, then others will be inspired by the change we can deliver. That, in turn, will give more power to our arm as BGS represents you nationally.

A word of caution – there is so much energy and enthusiasm for what we can do, that opportunities are proliferating more rapidly than we can accommodate. You can do almost anything, so long as it involves older people with frailty, but you can't do everything – opportunity comes with opportunity cost. Choose the opportunities where you can make the most impact – our documents on the BGS website can help you to do so.

So Happy New Year – somewhat Janus-faced, January brings great challenge and great opportunity. I think we're up the challenge. The opportunities are unprecedented.

Adam Gordon
BGS President
@adamgordon1978

BGS sounds the alarm for a difficult winter

In January 2023, we published a statement about protecting the rights of older people to health and social care. We wrote this statement as a response to the situation facing healthcare professionals across the country over the winter. The impact of the ongoing crisis in health and social care on older people was significant and led to many in the workforce feeling overwhelmed and disempowered. They were in no doubt that people died or were left permanently disabled because healthcare professionals were unable to provide the care that they desperately wanted to.

Our statement sounded the alarm on the damaging effects of poor care for older people, and set out both medium and long-term solutions to the crisis in health and social care Unfortunately, not enough has changed during 2023 and this winter threatens to be just as bad as the last. It is for this that reason we have updated and reissued our statement.

There has been some progress, such as the publication of the NHS Long Term Workforce Plan and the Intermediate Care Framework. However, older people are still getting stuck in hospital because of a lack of social care and rehabilitation in the community. In September 2023, 12,667 people were in hospital in England who no longer met the criteria to reside. This is only marginally down from the previous year when 13,514 remained in hospital who did not need to be there. Ambulance and emergency department waiting times have not improved and research shows that older people are more likely to wait longer in emergency departments than other age groups.

We are calling on governments across the UK to act now to ensure that this winter, older people have access to the health and social care that they need. At the time of going to print, 25 medical and third sector organisations have chosen to support our statement, showing the strength of feeling on this issue.

You can read the winter statement in full and see the list of organisations supporting it at www.bgs.org.uk/winterstatement2023-24

Toodle Pip

In her final column as Honorary Secretary, written before demitting at the end of November, Professor Anne Hendry looks back at an eventful four years in policy which has seen a pandemic, the publication of the BGS blueprint, and the start of a new project focusing on rehabilitation, reablement and recovery.

Sadly, this is my last editorial for BGS – who knew four years could go past so quickly? It has been a great privilege to work alongside the small but mighty team at BGS headquarters, Marjory Warren House, and to lend my support to the sterling work of fellow trustees on the Board. In passing the baton of Honorary Secretary to Ruth Law, followed in turn by Deb Gompertz, I know that the policy portfolio is in safe hands.

It's been a bumpy ride at times – trying to help BGS steer a course through the unprecedented circumstances of the pandemic that wrought such physical and psychological harm for our members and those they care for. We've had to find new ways to engage at the top of the house in the face of yet another NHS England reorganisation. We have some great influencers working at local level and in national roles across the UK to amplify our voice and get care for older people front and centre. Recently, Adam and Jugdeep have been prolific in their engagement with politicians and their advisers and with the media. It is encouraging that our messages are cutting through despite, or perhaps because of, the continuing health and social care crisis. With a general election next year, we need to be on the front foot in making the case for investment in better care for older people as the core users of our NHS and social care. To quote a colleague speaking about the health service in Ireland – older people are not our problem, they are our purpose!

> 'Framed around Pip as an older person who receives care and support, the report draws on the 'I'm Still Me' narrative and a survey by Yorkshire & Humber's Older People with Frailty Applied Research Collaboration to reflect what matters to older people.'

Our BGS blueprint, *Joining the dots* (**www.bgs.org.uk/blueprint**) sets out the case for investing in high quality, joined-up care and support to improve outcomes for older people and their carers, reduce demand, make our systems more resilient and achieve better value from funding and from the workforce. Please continue to promote the blueprint in your local system and champion the set of recommendations. Framed around Pip as an older person who receives care and support, the report draws on the 'I'm Still Me' narrative and a survey by Yorkshire & Humber's Older People with Frailty Applied Research Collaboration to reflect what matters to older people. The top two priorities in the survey were 'staying in my own home - living in my own home for as long as I can, with support if I need it'; and 'staying independent - being able to undertake daily and social activities.' Not just surviving but thriving!

As individual clinicians and in our teams I'm confident we are pursuing person-centred outcomes and helping older people live their best lives. As a society we have kicked off a new project to advocate for a step change in access to effective reablement and rehab services for older people so they have the best opportunity to recover their independence and wellbeing. BGS is already an active member of the Community Rehab Alliance of over 50 national charities and professional bodies across health and social care, who share a commitment to expanding access to rehabilitation to all those who need it and driving quality improvements to meet people's needs equitably. I am grateful to colleagues who volunteered to join our task and finish group and warmly welcome Lucy Aldridge, our new Policy Co-ordinator, who will be supporting the group along with BGS Policy Manager, Sally Greenbrook, and I. As well as setting out the evidence and describing different workforce models we want to gather examples of reablement and rehab services in different settings across the UK. Please email Lucy at **l.aldridge@bgs.org.uk** if you would like to share a short case study or video or perhaps write a blog about your local rehab service.

I welcome the recent publication of NHS England's new community rehabilitation and reablement model,[1] published alongside their intermediate care framework.[2] It's great to see the value of intermediate care being reaffirmed – so critical for recovery, for achieving discharge without delay and minimising readmissions. The community rehabilitation and reablement model aims to ensure that the individual (and their families) is at the centre of discussions and that transitions of care are seamless. I particularly like the tiered model or pyramid of expertise (pictured, right) – though I would prefer to upturn the pyramid to reflect the higher volume of activity and potential workforce from families, volunteers and voluntary sector partners. Last year the Scottish Government[3] and the Welsh Government[4] both published a person centred approach to recovery and rehabilitation both, each with a set of principles that will be food for thought for our group. Our challenge will be to present the compelling evidence on the benefits of rehab for older persons, including those who have delirium, dementia and the oldest old who often will have different trajectories. Some myth-busting and advocacy required...

Although my term of office as Honorary Secretary concluded in November I will stay close to this work on reablement, rehabilitation and recovery in the months ahead. I may also be involved in some proposed new BGS work on healthy ageing in collaboration with the Faculty of Public Health. It is now 36 years since I first experienced the joy of working in our specialty. In that time, I've held many different roles in a varied career in which I have learned so much from generous colleagues and stood on the shoulders of a few geriatric giants. I'm pleased I've had the opportunity to apply some of that experience in this BGS role over the last four years. I wish the BGS staff and my fellow trustees well as they continue our shared mission. I know all of our members share that mission.

Wherever you work, and in whatever discipline or role, may you remain passionate champions of high quality healthcare for older people and be inspiring role models for the next generation.

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Professor Anne Hendry
Outgoing BGS Honorary Secretary
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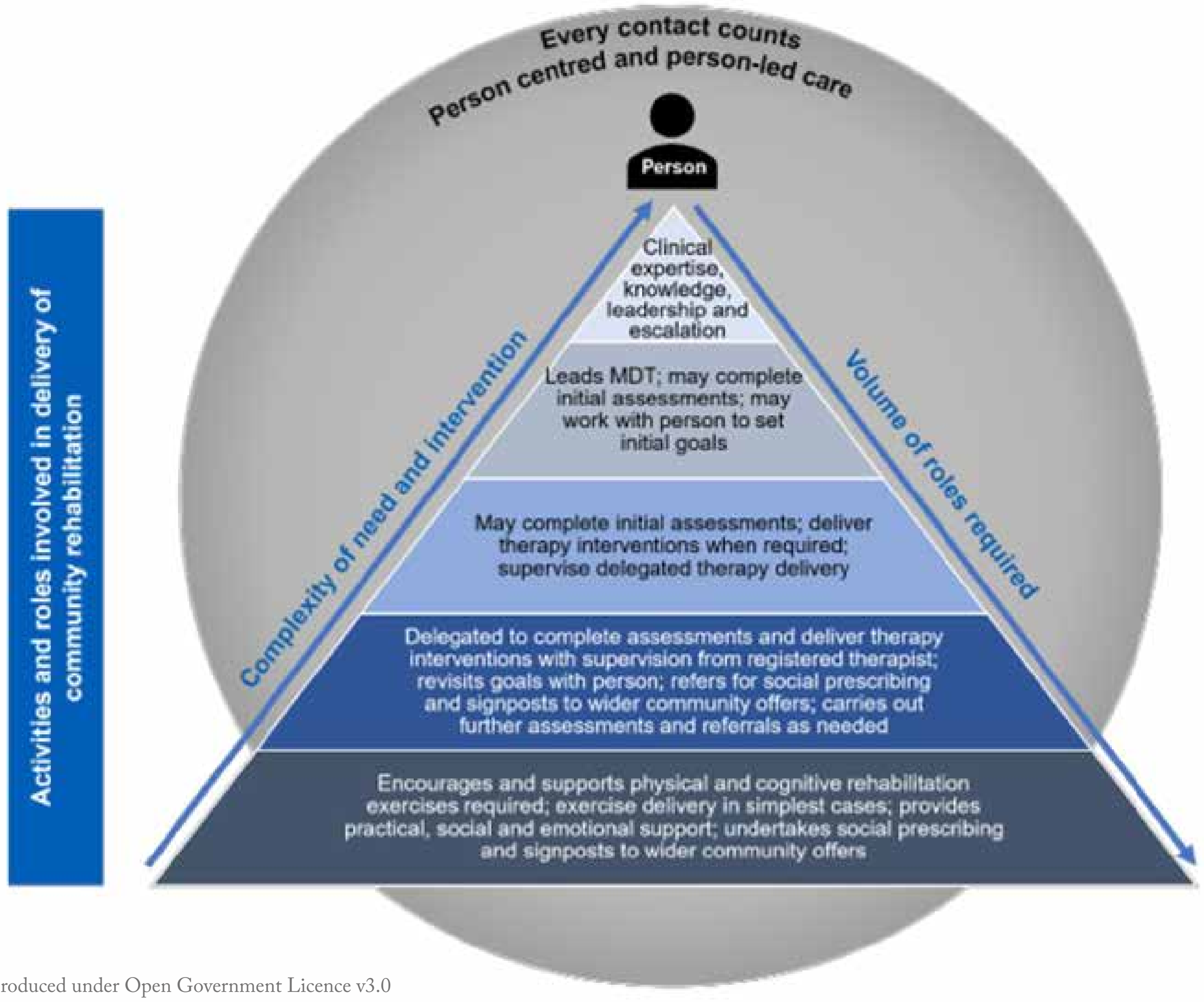
NHSE community rehabilitation and reablement model pyramid of expertise[1,2]



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The BGS is pleased to launch two new initiatives to support healthcare professionals and academics with an interest in undertaking research in the field of older people's medicine.

One of the BGS's five strategic ambitions is to promote research and the application of evidence-based knowledge to clinical practice in the care of older adults. The BGS is therefore excited to announce a new Research Hub, Research Project Grant and a new Vice President of Research and Academic Affairs.

The new BGS Research Hub is a suite of resources bringing together new and updated content from the BGS website, spanning the entire research journey.

The Research Hub provides practical and accessible advice for those who are ready to start their research career, or who are already involved in research but looking to take the next step. This free-to-access content is curated by the BGS Research and Academic Development Committee (RADC). The aim of the hub is to guide new and experienced researchers through the research process, from funding, ethics, and literature searching, right through to publication and presentation at professional conferences.

Videos featuring academics and clinicians from across the multidisciplinary team have been included to help inspire people who might be undecided about getting involved in research, offering an insight into the varied roles and backgrounds of those involved in age-related research.

The new hub is the latest in the BGS's series of content hubs, which already include the highly popular Frailty Hub, Delirium Hub and Quality Improvement (QI) Hub. As with the existing hubs, it is intended to act as a 'living' resource that will grow and evolve over time.

New BGS Research Project Grants

The BGS is currently accepting applications for grants to support researchers undertaking projects in the field of older people's health and care. These grants will support research-related activities undertaken by BGS members who work in the field of geriatric medicine or have an interest in ageing. Eligible applicants include non-consultant grade doctors, nurses, allied health professionals and pharmacists.

Each grant of up to £10,000 may be used for either clinical or non-clinical research, with up to two grants available per round. Applications for the first round open on 1 November 2023 and close on 1 March 2024. More information, including details of eligibility criteria and an application form, can be found at **www.bgs.org.uk/RPgrant**.

New BGS Vice President, Research and Academic Affairs: Professor Miles Witham

The Society is delighted to announce that Professor Miles Witham is the next BGS Vice President for Research and Academic Affairs. He will take up the post in November 2023, when the current Vice President, Dr Emily Henderson, demits from the post.

Dr Emily Henderson is our outgoing Vice President of Academic Affairs. For the past three years Emily has led the Research and Academic Development Committee (RADC). Emily has been instrumental in the planning and development of the Research Hub and pushing forward the BGS's agenda for research into the health and care of older people.

The BGS Vice President for Research and Academic Affairs plays a key role within the British Geriatrics Society. The role includes leading the Society's work to promote research into ageing and older people's healthcare, and the application of evidence-based knowledge to clinical practice across the continuum of care.

> 'The COVID pandemic has reminded us all just how important research is to underpin high-quality care for older people, and initiatives like the new Research Hub and Research Grants are an important part of building our capacity to support more and better research.'

Miles Witham is Professor of Trials for Older People in the AGE Research Group at Newcastle University. He is co-lead for the Ageing, Sarcopenia and Multimorbidity Theme, NIHR Newcastle Biomedical Research Centre, theme lead for Ageing and Long-Term Conditions, NIHR Newcastle MIC, and honorary Consultant Geriatrician at Newcastle upon Tyne Hospitals Foundation NHS Trust where he works as a community geriatrician.

His research focuses on ageing, sarcopenia and multiple long-term conditions (MLTC) using both clinical trials and routinely collected health and social care data.

Professor Miles Witham said: "I'm delighted to be taking up the post of BGS VP for Research and Academic Affairs and I look forward to building on the great work that Emily and colleagues have delivered over the last three years. The COVID pandemic has reminded us all just how important research is to underpin high-quality care for older people, and initiatives like the new Research Hub and Research Grants are an important part of building our capacity to support more and better research. I look forward to continuing our work to train the next generation of our researchers, get more colleagues involved in research from across all disciplines and professions, and raise the profile of research so that older people, clinicians and policymakers get the best possible evidence to inform care."

Get involved

We value your feedback on the new Research Hub. If you have any suggestions for improvements or additions to the information included, or are interested in getting involved with the BGS Research and Academic Development Committee (RADC), please let Joanna Gough, BGS Quality and Research Manager, know at **j.gough@bgs.org.uk**

WHO special issue on measuring healthy ageing

The World Health Organization (WHO), in collaboration with *Age and Ageing*, the journal of the British Geriatrics Society, has released a Special Issue on Measurements of Healthy Ageing. This Special Issue brings together the work of international professionals and experts from over 40 academic institutions, to identify the best available tools to measure what truly matters to older people – their intrinsic capacity and functional ability.

The global demographic shift towards an ageing population presents unique challenges and opportunities, with the number of people aged 60 and over expected to double by 2050 to nearly 2.4 billion.

Although people are living longer after the age of 60, the average length of time someone can expect to live in good health has not improved in many countries. This means more people are spending their older years in poor health or with disabilities. The collection of articles in this issue is a timely reaction to the growing need for greater knowledge and understanding about healthy ageing. The biggest challenge in measuring healthy ageing has been the wide range of ways to collect and analyse data. The publication of this Special Issue on Measurements of Healthy Ageing will help to ensure that measurement concepts are clearly defined and offer a route to greater harmonisation of measurement approaches.

The partnership between WHO and *Age and Ageing* journal marks a significant step towards changing the global perception of ageing and addressing knowledge gaps on measurement. By understanding and addressing the unique needs and abilities of older people, societies can progress towards a world where everyone ages with dignity and fulfilment.

For more information and read the special issue, visit https://www.bgs.org.uk/MOHA

NEW RESOURCE OUT NOW

BGS FRONT DOOR FRAILTY

Advice on setting up services


BGS

Front door frailty: Advice on setting up services

www.bgs.org.uk/FrontDoorFrailty #FrontDoorFrailty

The BGS has published a new resource aimed at supporting healthcare professionals who want to offer a front door frailty (FDF) service to older people presenting at emergency departments (EDs).

Health and social care services across the UK are under immense pressure. Images of ambulances queuing outside EDs and horror stories of older people lying on the floor for hours waiting for an ambulance after a fall or waiting for hours on trolleys in ED have become commonplace across the media. Evidence shows that older people wait longer than other age groups to be assessed in the ED and to be seen by a medical specialist. Older people who are admitted to hospital are more likely to face lengthy hospital stays and are often unable to be discharged because of a lack of social care or rehabilitation in the community. As winter approaches, the coming months are likely to be tough for the NHS and social care and it is with this in mind that we have published this resource now with the hope that systems may find it helpful for their winter planning.

> 'Front door frailty services contribute to hospitals operating more efficiently with fewer people experiencing long waits in ED and fewer people getting delayed in hospital, unable to be discharged. This resource shares the experiences of those who work in established services and is intended to support colleagues who wish to get started in this area.'

Identification of frailty at the hospital front door can help trigger early comprehensive geriatric assessment (CGA) and ensure that older people with frailty are diverted to the most appropriate services within the hospital as quickly as possible and, where possible, discharged home on the same day. As well as improving the experience and health outcomes of older people attending hospital, FDF services improve patient flow and reduce pressure on the whole hospital system.

There is no 'right way' to do FDF – the service provided will depend on factors such as the hospital estate, the workforce available and the needs of the local population. With this in mind, we have set out five principles that should underpin FDF services and provided a series of tips about establishing services from those who have been through the experience.

Dr Tom Downes, BGS Vice President for Clinical Quality, said: "Front door frailty services have had a positive impact everywhere they have been implemented effectively. They improve patient experience by reducing unnecessary admissions and helping older people to get back home the same day. Front door frailty services contribute to hospitals operating more efficiently with fewer people experiencing long waits in ED and fewer people getting delayed in hospital unable to be discharged."

"This resource shares the experiences of those who work in established services and is intended to support colleagues who wish to get started in this area. We very much hope that healthcare professionals across the country will find this useful as they work towards establishing front door frailty services."

To read the resource in full, please visit www.bgs.org.uk/FrontDoorFrailty

A new British Geriatrics Society report makes key recommendations for the effective use of a national minimum dataset to deliver the best possible care in UK care homes and domiciliary care.

The BGS hosted an event in London on 12 September 2023 to discuss ideas and best practice around a minimum dataset for care homes. Health and social care practitioners, academics, system leaders and policymakers came together to consider how the collection and use of data could help to inform better care. The BGS has subsequently published a report from that event.

Smarter data, better care: Empowering care homes to use data to transform quality of care sets out the barriers to and opportunities for collecting standardised care data. It contains insights from the National Institute of Health Research DACHA study and from interRAI as well as from other national and international studies using social care data. It summarises the accumulated experience of several research and data teams and reflects on the "state of the art" in minimum datasets.

> ‘The troubling revelations from recent hearings at the COVID inquiry remind us how little policymakers and healthcare leaders knew about care homes at the beginning of 2020. This was, in part, due to a lack of data. We must never be in a situation again where we are asked to make life or death decisions about the most vulnerable members of our society without the data to do so.’

The COVID-19 pandemic gave new impetus to transforming how social care data is collected, shared and used. There is a genuine appetite across the health and care sector to support those providing, receiving and commissioning care through better use of data.

In the report, the BGS makes 12 recommendations for policymakers and regulators to consider. This includes ensuring a national minimum dataset is genuinely a resource for better care, by ensuring that its format, content and method of implementation are meaningful and useful for people living in care homes and those caring for them.

Professor Adam Gordon, President of the British Geriatrics Society, said: "The troubling revelations from recent hearings at the COVID inquiry remind us how little policymakers and healthcare leaders knew about care homes at the beginning of 2020. This was, in part, due to a lack of data. We must never be in a situation again where we are asked to make life or death decisions about the most vulnerable members of our society without the data to do so. Data also has an important role to play in delivering the best care day-to-day. With this in mind, I'm delighted that the BGS is publishing this report. We hope that this helps give policymakers impetus towards commissioning a minimum dataset in long term care homes that is robust enough to inform care decisions. It is essential that they do so with urgency."

To read the report and recommendations in full, visit www.bgs.org.uk/CareHomesData

BGS responds to ongoing UK COVID Inquiry

The impact of the COVID-19 pandemic was felt in all sectors of society, and by those of all ages and backgrounds. There is no doubt, however, that older people with frailty were among those most adversely affected.

More than nine out of ten (92.3%) COVID-19 deaths were in people aged 60 and above and over half (58.3%) were in those aged 80 and over. People aged over 85 were 15 times more likely to be admitted to hospital with COVID-19 than those of working age. Focusing on the most vulnerable older people, of the 193,266 deaths in England to date from COVID-19, 36,197 were in care homes. To put this in perspective, that is 19% of COVID deaths occurring in a group who make up less than 1% of the population. During the first wave of the COVID-19 pandemic, almost half of all deaths were among those living in the care home sector.

This was a humanitarian tragedy of devastating proportions. We lost family members, friends and, for those of us working in the health and social care professions, patients, clients and colleagues we cared dearly about. Many BGS members are still recovering from their harrowing experiences during the pandemic. We have supported many families for whom life will never be the same.

With this in mind, we have watched the UK COVID-19 Inquiry closely. We have done so in the knowledge that the challenge facing our country in early 2020 was unprecedented in modern times, and that difficult decisions were made under substantial pressure. Nevertheless, we have watched it with growing concern. Most worrying has been the evidence that older people, particularly those living with frailty and multimorbidity, were not given specific consideration during the early stages of pandemic planning. While the best epidemiologists and virologists were called on to advise government early in the pandemic, it was not until the autumn of 2020 that experts from the BGS were finally invited to provide advice as part of the Social Care Working Group of the Scientific Advisory Group for Emergencies (SAGE).

Some decisions made during the pandemic remain contentious, including the discharge of large numbers of older people from hospital to care homes early in the pandemic. We know from publicly available papers by SAGE that this decision will have contributed in part to some outbreaks and deaths in care homes. We also know, from evidence provided to the Inquiry, that those who instituted this policy had considered that such outbreaks might happen. These decisions were ostensibly taken to protect intensive care capacity in hospital and to protect the hospital sector from becoming overwhelmed more generally.

This policy had far-reaching implications for care home residents and staff. We know from our membership, and from the evidence presented to the Inquiry, that services supporting older people were among the last to be able to access effective personal protective equipment (PPE) and testing for SARS-CoV-2. These are all examples of decisions where one population group was prioritised over another. In the early stages of the pandemic such decisions were highly detrimental for older people living with frailty and multimorbidity.

The BGS had not planned to issue a statement on the Inquiry until nearer its conclusion, but the pressure from our membership to speak now is substantial. They are angry at much of what is emerging from the Inquiry and we feel that we should reflect that anger. It is important that lessons are genuinely learned. We hope that the Inquiry, as well as those giving evidence to it, will consider whether ageism impacted upon decisions made as part of pandemic planning and pandemic response. We ask the Inquiry to report, frankly, upon whether more could have been done to protect the most vulnerable groups in society. And we beseech the Inquiry to ensure that future pandemic responses call upon the expertise of health and social care professionals, including those from the care home sector, who are specialists in ageing and frailty. This will ensure that policy recommendations draw from real-world experience alongside the best advice that epidemiologists, virologists and public health specialists have to offer.

Professor Adam Gordon, President of the British Geriatrics Society, said: "I hear from BGS members on a daily basis at the moment about how concerned they are at the revelations from the COVID-19 Inquiry. We have seen evidence presented which is, at best, indicative of tacit ageism. Older people, particularly those living with frailty and long-term conditions, including care home residents, were not given sufficient consideration in the early stages of the pandemic response. Decisions about how people most likely to be impacted by the virus would use, and need to use, healthcare resources, were made without the input of professionals who routinely provide frontline healthcare to that group, namely older people. Had there been more recognition of the rights of the largest group using health and social care and the expertise of those who care for them, we believe the quality of care delivered would have been improved and lives could have been saved."

What matters to ME

The delivery of person-centred care is as varied as people themselves. As healthcare professionals working with older people know only too well, the older a person is, the more life they have lived, and the more unique their experiences, values and health needs become. Any time wasted on care or treatment which is detrimental to their own goals is precious time that could be spent living in a way that better aligns with their own wishes.

While there are huge opportunities when it comes to delivering age-attuned person-centred care that reflects the needs of an individual, therein too lies the challenge – everyone is different, and you cannot apply one person's wishes to someone else. Patient-centredness a mindset as much as a process, and getting into the habit of avoiding assumptions and asking the person in front of you what matters to them is something that comes more naturally to those working with older people than perhaps other specialties within medicine or healthcare.

With this in mind, we spoke to two older people who participate in patient and public involvement and engagement (PPIE) at the University of Exeter, which aims to guide researchers and help them consider the patient voice. The two participants kindly took the time to talk about their goals and priorities when it comes to their health, and why they feel it is important for healthcare professionals and researchers alike to listen to their needs and wishes.

Pat W

Pat, pictured left, has an adventurous spirit and a love of movement. Now 78, she has always lived an active life. "I was brought up in a small town in Wiltshire, so if you didn't get out and do exercise there wasn't much to do," she explains, setting the scene for her love of physical pursuits. "I've run quite a few marathons and half marathons in different parts of the world. I've got an international certificate so I could charter yachts anywhere, and I have sailed across the Channel quite a few times. I've travelled all over the world, often on my own, and been to Everest Base camp twice." Acknowledging that this probably makes her fitter than most people her age, she adds "I'm not your usual 'elderly person,' - or 'older person', as I prefer." Sharing her feelings about her own experience of ageing, she speaks about it in positive terms. "I welcome new challenges" she says, "but sometimes you just need a bit of support to do what you want to do." Noting that with age comes experience, she adds "I think as you get older, you get more confident and you know when to ask for help without worrying about what other people think."

Her positive outlook is reflected in her thoughts about what 'good health' means to her personally. "I think what good health means to me is trying to be positive, having friends, being on the allotment, continuing with yoga class as well as keeping active and maintaining my mobility. It's important for me to feel involved, that the voice of older people is heard and that I can make a difference, especially with my PPIE work."

"One thing that I've noticed is that some healthcare professionals sometimes don't listen actively to what I'm trying to say ," she says when asked whether she felt healthcare staff understood what her health priorities were. "It's not just about asking questions and ticking a box, it's showing interest and really listening to what that person's saying and checking for understanding. And for me, that needs to be a starting point as this can save time."

The biggest thing healthcare professionals could do to make a difference, in Pat's opinion, is "really listening, openly discussing a person's needs, making sure the person is well informed, and explaining the next steps - and then follow up on that after an agreed period of time, which sometimes doesn't happen." Pat said that one of highlights of 2023 was doing a short presentation with two other PPIE partners about their involvement on the NIHR Applied Research Collaborations' national programme in Healthy Ageing, Dementia and Frailty at the BGS Autumn Meeting.

Andrew T

Andrew is an 81-year-old retired veterinary surgeon (pictured right) who enjoys keeping his scientific mind active by taking part in PPIE work. "It takes me back 50 years," he says, "and I'm having to really revisit all the science that I did at university a very long time ago." Crediting his pet dog with staying active and giving him a sense of purpose, he explains: "I have a dog who gets walked every day, and in a way that that's quite important… it gives you something to get up to do in the mornings, regardless of how you feel, which I think is a really good thing."

Discussing his feelings around growing older, he too feels quite positive about the process. "I think you have to be positive about it. Actually, when I say positive, I mean you have to accept that this is something that's happening. Having watched my father who had a stroke at 79 and passed away at 83 and who never came to terms with ageing, I think one of the most important things for us is to actually come to terms with the process."

Talking about what good health means to him, he shares: "Good health is doing as much as you can, I think… I do feel strongly that if you want to keep healthy, you have to keep both mind and body going. Bad health to me would be something that actually stopped me going out and walking the dog or going out and spending half an hour at the allotment."

Reflecting on whether he feels understood by healthcare professionals when talking about his health priorities, he explains: "There is sometimes a lack of appreciation among health professionals about the fact that people, as they get old, feel they have limited time on this earth and want to make the best of it. Therefore every day matters."

"I think they do tend to look at what's wrong with you and say, right, we'll treat that - rather than saying, well, actually, what do you want out of life and what can we do to make it better?" Yet he remians pragmatic and understanding of the fact that sometimes it's the system, rather than individual staff, which are the issue. "Health professionals probably can't do anything about it at the moment, it's not a big issue, I'm not sure it comes high up on the priority list But maybe there are small things that they might be able to do."

"Being in hospital for a fortnight when [you] could have come out the next day if there had been any support… that, I think, is really draining on older people."

Amy Brewerton
BGS Publications and Website Editor
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Older patients' involvement in research

Health and social care research is increasingly required to include patients, those with lived experience, members of the public, potential patients, carers and people who use health and social care services. Patient and public involvement and engagement (PPIE) can be traced back in the UK by about 50 years, to ensure people have a voice in research and care services.

Older people, in particular those living with frailty or complex health and social care needs, are considered an underserved population in health and care research.

Research can often be developed and designed without their needs or what is important to them being considered. Older people and their families can have different perspectives of health and care that expert clinicians, practitioners and researchers may miss or not understand. Meaningful PPIE brings added value by ensuring researchers do the right research, in the best way, and with the best chance of producing the information and interventions people need to optimise their health and wellbeing. By working in this way we ensure our practice is not just evidence-based but also person-centred. So we must advocate for the older person's voice being heard in research and practice.

PPIE adds value at all stages of research from identifying important research questions through to implementing research into practice. To do PPIE well requires time and resources. We wouldn't expect funders to invest in a randomised controlled trial without the time and resources for a statistician, would we?

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ELEVATING EVIDENCE for PERSON-CENTRED CARE

Professor Rowan Harwood, Editor-in-Chief of *Age and Ageing* journal, highlights the lack of research into person-centred care, and sets out the challenges of reflecting its true value in emperical evidence.

The idea of person-centred care was originally introduced as a counter to medical paternalism. It tried to move beyond the biological medical model, of diagnosis and provision of specific curative treatment, to accommodate wider elements of people's lives. This meant knowing about all aspects of a person's health, function, relationships, environment and their preferences or priorities, and taking account of them in treatment decisions. In many spheres of practice – chronic disease, multimorbidity, disability, mental health or at the end of life – this makes abundant sense.

Person-centred care has become the dominant way to understand the experience of wellbeing or distress in dementia. It aims to address fundamental human psychological needs, for comfort, identity, inclusion, attachment and occupation. It moves us away from seeing problems in dementia primarily as a feature of the disease, for which, unfortunately, specific medical treatments are disappointing. Instead, it emphasises context and relationships, things we may be able to do something about. It does not deny the value of medical assessment or treatment, including for diagnosing and understanding the disease, and for intercurrent illnesses, co-morbidities or palliating distressing symptoms, but accepts its limitations.

Person-centred care also addresses the ethical imperative for good decision-making, respecting autonomy and choice. Preferences, values and priorities may differ greatly between individuals. Imposing the doctor's world view does not necessarily best serve the individual patients' interests in a free world. This is well reflected in most western mental capacity legislation, and guidance on shared decision-making. Sociologist Alison Pilnick has highlighted, however, the risk that 'if choice and control are seen as properly belonging exclusively to patients, there is no longer any clear place for medical expertise'. However, such expertise provides the foundation for shared-decision making. Pilnick draws a distinction between medial 'expertise', and medical 'authority'. Person-centredness does not abrogate the need for good physicians and multidisciplinary healthcare colleagues.

> 'Health gain is often seen quite narrowly – in terms of mortality, cure or reduced disability. Where medical treatment is of limited efficacy, we need to recognise inclusion, activity and identity as things we value.'

The reason that person-centred care is difficult in practice is often because of constraints and competing priorities. We use pathways, for example in stroke or cancer, because they deliver more consistent care that leads to better outcomes. We often operate when resources are insufficient, so we are called upon to sacrifice individual experience for a greater good, for example when patients are moved between wards to make way for new admissions. Person-centred care takes time, resources, and requires explicit work from professionals. It needs training and skill. In attempting to promote efficiency and define limited organisational responsibilities, healthcare can return to the reductionist medical past. A good experience of healthcare, and attention to psychological and emotional wellbeing, may be central to how patients and their families want to be treated, but not may not be seen as the responsibility of health services.

The medical model breaks down when its assumptions are violated. That diseases occur singly, in previously fit people, with the capacity to recover from them. And that we have specific treatments that work to provide a cure. Of course, this is not the case, and has never been. In fact, it applies for relatively few conditions – some infections, some cancers, some nutritional deficiencies, some surgical procedures.

Person-centred care is a *sine qua non* of geriatric medical practice – something absolutely central or essential. The 'necessity' of system-centred measures that compromise person-centredness must, at minimum, be acknowledged, even when we must reluctantly accept them.

In my experience, person-centred care 'works', but many empirical studies have failed to demonstrate this. Health gain is often seen quite narrowly – in terms of mortality, cure or reduced disability. Where medical treatment is of limited efficacy, we need to recognise inclusion, activity and identity as things we value. Some disciplines value therapeutic relationship in its own right. A new challenge for research.

Professor Rowan Harwood
Editor-in-Chief, *Age and Ageing* journal

The future of ageing:

Ethical considerations in research and innovation

With so much going now in the world of ageing research and technology, how can we ensure that developments are person-centred and benefit the older people who need them most? Science has a history of both ignoring and exploiting marginalised groups in favour of gains for the healthy and rich, and most people are keen to rectify these wrongs by acting to improve our research practices.

DEMONSTRATING TRUSTWORTHINESS
- How are these values and principles reflected in oversight arrangements for the research?
- How are diverse older adults involved in these arrangements? (e.g., via an oversight group)
- What arrangements are there for communicating research findings to those who take part, and those likely to be affected by it?

Supporting flourishing in older age
- How does this research promote the needs, opportunities, values, and goals of older adults?
- Does it include the ability to test for harms as well as potential benefits?
- How does it support human relationships and social connectedness (within communities and across generations)?

Shifting power
- How can older adults control the way the technology or intervention works for them?
- How will it enhance their control over how they wish to live their lives?

Promoting equity
- What active steps are included in this research to reduce existing inequalities?
- How will it meet the needs and aspirations of older adults who are most disadvantaged?
- How might any barriers to access be addressed?

Challenging ageism
- How does this research recognise the capacity, skills and knowledge of older adults?
- How have older adults, representing a full range of backgrounds and experiences, been involved in identifying the needs to which this research aims to respond?

ENABLING SUSTAINABILITY
- What are the resource inputs (energy, finance, infrastructure) for this research?
- What are the longer-term resource implications of this research/innovation if translated successfully?
- Has priority been given to preventative approaches that reduce the need for later or more intrusive interventions?

The ethical framework that was developed by the Nuffield Council of Bioethics can be seen above in the diagram from the report. It asks questions of us, as researchers, which allow us to consider our research in person-centred way.

In thinking about the future of ageing research and technology from an ethical perspective, I must admit I was intimidated. Partly by the enormity of the topic and partly by the panel of experts in ethics, ageing and technology who had been assembled at the Nuffield Council of Bioethics. I went to the first meeting of the steering group nervous. I needn't have been. Our chair, Bella Starling, was welcoming and the group members contributed as equals drawing on our expertise and experience in our fields, as well as our individual and family experiences of ageing and technology. The team at the council kept us within the boundaries of the subject and pulled everything together into a final report.

We ended up with 15 recommendations for all involved in research and technology development for older people. They range from actions on inclusion for marginalised groups to guidance on interdisciplinary research to ideas for accreditation of technologies. You can read the whole report and recommendations here: **www.nuffieldbioethics.org/publications/future-of-ageing**

As well as contributing as a geriatrician, I also used my experience as a comics artist and teacher to do a workshop with older people from Bristol as part of the engagement strand of work (the resulting comic is here: **https://tinyurl.com/NCBcomic**).

The team at Nuffield Council also asked if I would do some comics for the final report, which feature throughout, and example is shown left.

Muna Al-Jawad
Consultant Geriatrician, University Hospitals Sussex; Senior Lecturer in Medical Education at Brighton and Sussex Medical School

Growing older with HIV

Thanks to advances in treatment, people are living longer than ever before with HIV, and many are being diagnosed later in life. This brings about new challenges for care.

There are more than 90,000 people living with HIV in the UK, with very high treatment coverage, meaning many people with HIV live active and healthy lives. Approximately half of these people are aged 50 and over.[1] Additionally, one in six new cases of HIV in Europe is in someone over the age of 50, and often diagnosed late, meaning the virus has already started to damage the immune system.[2]

In the UK in 2021, 59% of people aged 50-64 were diagnosed late, as were 73% aged 65+ (UK average 46%).[3] Late HIV diagnosis has serious health consequences, with older people having significantly higher mortality rates than any other demographic. The one-year mortality rate of people diagnosed late aged 65 and over is 200 deaths per 1,000 people.[4]

Effective antiretroviral therapy and better management of co-morbidities and opportunistic infections means people with HIV are living into later life. They also ensure HIV cannot be passed on to people's sexual partners. Antiretroviral therapy reduces the level of HIV to an 'undetectable' level, at which point it is impossible for HIV transmission to occur during sex. People with HIV often refer to this as 'undetectable = untransmittable' or 'U=U'. Raising awareness of this has been transformative to people's lives, enabling them to have sex without fear, and challenge internalised feelings of shame and guilt.

HIV prevention in older people

Discussion around sexuality, intimacy and relationships is an often overlooked part of Comprehensive Geriatric Assessment (CGA). It is important that older adults can be open and honest about their sexuality and sexual health when accessing healthcare.

Sexually active older people should be encouraged to test for HIV and sexually transmitted infections (STIs) regularly. While condoms are still an effective method for preventing the transmission of HIV and other STIs, some people may use additional interventions to protect themselves from HIV such as pre-exposure prophylaxis (PrEP), a medication taken by HIV-negative people before and after sex that reduces the risk of acquiring HIV. The choice of medication for PrEP is be influenced by co-morbidities and concurrent medications, so geriatricians should be aware of their local sexual health services in order to support people in accessing them.

HIV-related stigma

Stigma remains the biggest hurdle to people living with HIV accessing healthcare who are often worried about having to explain their HIV status to healthcare professionals. A study found that both anticipated or experienced stigma was a key issue, with 35% of respondents worried that they would be treated differently, 14% having experienced discrimination in healthcare and 11% having been denied or refused a treatment or procedure.[5] Being under the care of someone who understands what it means to live with HIV today, without judgement or asking unnecessary questions, such as 'how were you infected?' can make all the difference to someone in need of support.

Complex care needs

Many people with HIV experience increasingly complex health needs as they grow older. People diagnosed before 1996 had little to no access to effective medication, and those that did experienced high levels of toxicity, and live with the long-term side effects today. This cohort also experience ongoing grief or post-traumatic stress due to the loss of their friends and partners, with many now living with what they describe as 'survivors guilt'.

Positive Voices: the National Survey of People Living with HIV[6] found that 62% of people with HIV aged 55 and older were prescribed additional medication to their HIV therapy within the past four weeks. The survey also reported that 82% of this age group had at least one additional long-term condition, and 36% had a mental health condition.[6]

> 'Many people with HIV experience increasingly complex health needs as they grow older'

Supporting people to age well with HIV

Terrence Higgins Trust provide opportunities for people growing older with HIV to connect with each other and share experiences with their peers. Our support groups have focused on particular areas which people accessing our services have told us are important to them. Utilising co-production principles we have designed workshops to explore areas including relationships and sex, and improving physical wellbeing. We also provide regular social activities for people aged 50 and over, and our 'Before 96' group provides a space for people with long-term diagnosed HIV to meet and build friendships.

The Africa Advocacy Foundation promotes access to health, education, and other opportunities for disadvantaged African people through practical support, advocacy, campaigns, information, advice, guidance and training. In partnership with Terrence Higgins Trust they have also run workshops covering the HIV experiences of members, past present and future. These brought to light concerns members had around ageing with HIV as a migrant to this country. Expertise was tailored to the needs and concerns raised during the workshops, which included funeral arrangements both in the UK and repatriation options; retirement options, whether in one's home or in a residential care setting, and if these facilities will have culturally tailored facilities (e.g. access to African hairdressers); faith settings and the role stigma plays across the board.

They also helped empower and support members to navigate the health care system as they age, including managing comorbidities, simplified medical information tailored to this community, and navigating social care, including addressing the distrust in health and social care settings.

Both organisations work to educate and empower people growing older with HIV with the knowledge and expertise they need to have meaningful relationships with the healthcare professionals they interact with.

Where do Geriatricians fit?

HIV is associated with high rates of multimorbidity and frailty making geriatricians well positioned to contribute to the care of people living with HIV.[7] Many people with HIV have been under the care of the same specialist or service for several years - even decades, in some cases. They value these relationships, and in order to support them with other ailments and health problems, it is important they can feel comfortable and safe to share their unique needs and concerns when interacting with new healthcare professionals.

A 2016 study showed that 23 out of 98 people with HIV identified the need for a dedicated ageing service.[8] Guidelines produced by the European AIDS Clinical Society (EACS) emphasises the importance of frailty screening and CGA, while those produced by the British HIV Association (BHIVA) promote incorporating geriatricians into the care of complex older people living with HIV.[9,10]

Currently there are many barriers to the routine involvement of geriatricians into the care of people living with HIV including limited knowledge around HIV and its treatment, HIV screening and specific issues related to older people living with HIV.[11] This is alongside diverse experiences in managing people living with HIV or older LGBTQ+ people.[11]

Conditions common in older people living with HIV include common geriatric problems such as falls, cognitive impairment, depression, continence problems and polypharmacy.[6,11] As a result, several joint HIV and geriatric medicine services have been established such as the 'Sage Clinic' at the Royal Free Hospital in London[12] and the 'Silver Clinic' in Brighton.[14] This model may not be feasible everywhere due to issues of either supply or demand, with alternatives including incorporating geriatricians into multidisciplinary meetings about complex patients, or having clear referral pathways into existing ageing services for HIV clinicians to follow.

Conclusion

What is clear is that HIV will soon become a condition of older people, so geriatricians must ensure they are prepared to meet the needs of this population to ensure effective and stigma-free healthcare.

Useful resources

- **Liverpool HIV Drug Interactions online tool**
  This online tool provides a clinically useful, reliable, comprehensive, up-to-date, evidence-based drug-drug interaction resource, freely available to healthcare workers, patients and researchers.
  www.hiv-druginteractions.org

- **The British HIV Association (BHIVA) E-Learning modules (open access)**
  BHIVA E-Learning modules are based on BHIVA guidelines and are a great way of getting free CPD in HIV Care.
  www.bhiva.org/ELearning

- **Terrence Higgins Trust 'Can't Pass It On' training for healthcare professionals**
  Our training course for healthcare professionals aims

to increase awareness and understanding of Can't Pass It On/Undetectable = Untransmittable, enabling you to competently discuss this in practice with patients and colleagues
www.tht.org.uk/CPIOtraining

Find out more

- **Terrence Higgins Trust** is the UK's leading HIV and sexual health charity. We support people living with HIV to live well, challenge HIV-related stigma and help people using our services to achieve good sexual health.
www.tht.org.uk

- **Africa Advocacy Foundation** supports and empowers vulnerable and disadvantaged people. We are a community-led initiative that aims to equip diaspora communities and marginalised people with the tools they need to find better health, safety, prosperity and opportunity to lead fulfilling and happy lives.
www.africadvocacy.org

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If you have any questions about this article and would like further information please contact livingwell@tht.org.uk. If you would like clinical advice regarding the care of an older person living with HIV please contact howell.jones@nhs.net

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Last wishes

Following her experience of being present to advocate for her late father when he was approaching the end of his life, Dr Irene Wagner asks if more evidence is needed about the impact of family visitors in hospital.

In the early evening of Wednesday 27 September 2006, I was phoned by my father who practically and calmly explained to me he had acute myeloid leukaemia (AML). My father was two months off turning 80 years old, a cardiologist and general physician, still working part time and cognitively intact. He had felt a little breathless, so took himself to our local pathology service for a series of baseline bloods. The pathology service's haematologist rang him with the results of his full blood examination (FBE), which revealed a total white cell count (WCC) of more than 300,000. To my father's bald statement, my response was "how did you make THAT diagnosis?", to which he replied he had examined himself and as he had no lymphadenopathy, it was not acute lymphocytic leukaemia!

The following day he went to work and on Friday saw the haemato-oncologist, who wondered if it might be a chronic leukaemia, given the high WCC. Because of the large tumour burden my father's prognosis was poor.

On Sunday morning at 5am my mother rang me to say my father was breathless, restless and his pulse was racing. I picked up my stethoscope and prescription pad and drove to their home. My assumption was Dad had developed atrial fibrillation (AF) with a rapid rate, possibly some heart failure and an infection. On arrival Dad failed to recognise me and refused to let me examine him. It was clear he was very unwell and we would not be able to meet his care needs at home. Thus, we took him to hospital.

In the Emergency Department (ED) Dad had an oxygen saturation on room air of 60% and was in AF with a rate of 140/minute. No wonder he had a delirium! After a baseline workup it was decided he most likely had an infection resulting in the AF and a degree of heart failure. Because of the severity of his hypoxia, ED medical staff were keen to intubate him. My father had always been very specific – he never wanted to be admitted to an ICU on a ventilator. I explained this and stated, we agreed to him being treated with high flow O2, IV antibiotics and diuretics. Three times the ED medical staff approached me, asking if I was certain about refusing their recommendation to intubate and ventilate my father. Despite having been a consultant physician for 15 years, their repeated questioning started to worry me.

By 8am my mother and I had been joined by two of my three siblings, as one brother was interstate. My family members, who all knew my father's wishes, were comfortable with the decisions I had made on behalf of Dad, and were in agreement with my refusal of intubation and ventilation on his behalf.

Dad was admitted to the hospital's coronary care unit. Like many patients delirious due to hypoxia, Dad kept pulling off the O2 mask. I firmly put it back on. He wanted to lie flat, and because of the furosemide, wanted to drink while horizontal. As a geriatrician this was a no-no. I made him sit up in his electric bed with all oral intake, as I was not going to be party to him aspirating!

My siblings and I agreed to have one of us at his bedside for the rest of that day, as it was beyond our mother's ability to manage him alone. By the time I handed over Dad's care to my sister late afternoon, he was very cross with me. He stated he was only staying in hospital to keep me happy, he would go home tomorrow and take his antibiotics orally there. My explanation, the antibiotic he was on was not available in an oral form, he could not comprehend. I instructed my mother firmly that she was not to assist him to discharge himself, as we would not have been able to manage his care needs at home. If Dad wanted to discharge himself, then he would need to dress himself, pack his bag, walk to the front of the hospital and find a taxi to take him home.

I had informed the ward staff that if there were any concerns with Dad overnight, especially because of the delirium, then they were to ring me. No phone call resulted. Monday morning at 7am I rang the ward and asked how Dad was, to be informed he was compos mentis, shaving, while intermittently and briefly taking his O2 mask off.

Monday evening after work I visited him. By this time the diagnosis of AML had been confirmed. My father was delighted an echo had shown no evidence of cardiac failure; rather he was hypovolaemic so was receiving IV fluids. The reason for his severe hypoxia was, the leukaemic cells were sludging up his pulmonary vasculature. Pain was not an issue and cognitively he was back to normal. He had discussions regarding chemotherapy for the leukaemia, but on the basis of his rapidly increasing WCC it was felt treatment would not achieve anything positive, so this was not pursued.

Interestingly, he informed me he would not be able to last long, indicating how very unwell he felt. I asked him if he could hang on until the end of the week, as he had many relatives, friends and colleagues who would want to visit him. He said "no". I asked him if he could hang on till Wednesday, as my brother from interstate was arriving, and again he said "no". So, I rang my brother and made it clear to him he had to arrive the following morning, which he did.

Tuesday morning the entire family, including his three grandchildren aged between 10 and 12, were in the hospital. By this time Dad's WCC was more than 500,000. He was experiencing pain from his enlarging liver and spleen and was commenced on a morphine infusion. We were clearly told his prognosis was limited. I returned to work, but visited him in the early evening with my family. Suddenly, at about 8pm Dad became very restless, moving about the bed and clearly uncomfortable. With his agreement I got him an extra bolus of IV morphine. I sent my husband and two children home, indicating I would not be able to leave until I knew Dad was comfortable. By 10pm Dad was lying peacefully in his bed. He had pulled off his O2 mask. I put it back on his face, but some minutes later he removed it again. I took this to mean, he felt it was time to die, so did not replace it again. At 11pm I left the hospital, planning to return early the following morning.

I was rung at 2am and informed he had died. He never roused after the bolus morphine.

This experience taught me several things:

1. The importance of having those end-of-life discussions with your loved ones, whom you might have to advocate for, ideally on more than one occasion, so when acute situations arise you have the confidence to stand up for what the patient wanted for themselves. Had I agreed to Dad being intubated and ventilated, he would have died shortly afterwards, because we turned off the machines. I would have deprived him and all the people who visited him, including myself, of their last opportunity to talk.
2. The vital role family members have in providing bedside care for patients with delirium. I am firmly of the opinion, had I not been an absolute dragon of a carer in regards to keeping the O2 mask on his face and making him sit up in bed, he would not have been compos mentis the following day.
3. Patients dying feel dreadful and 'yuck'. While we can manage specific symptoms, including pain, nausea and constipation, we do not have an anti-yuck drug.

I provide an aged care liaison service to a large general medical service in an Australian health service. Pre-COVID we welcomed visitors of these patients, many of whom have cognitive dysfunction due to dementia and/or delirium, without being fixated on them visiting between set hours. Once COVID arrived all visitors were banned from the hospital unless the patient was dying. This resulted in patients being discharged without them, or their families, understanding what had happened to them while an inpatient. Our medical staff were talking to their patients; the patients were just too unwell to take it in and so could not inform their families of what had occurred. Staff were so busy, they did not have the time to ring family members routinely to update them on what had occurred to the patient during their admission. Anecdotally, my experience was that the episodes of delirium our patients experienced were more severe, as we did not have family members by their bedside to reorientate and reassure them.

In recent times, once our restrictions on visitors post-COVID eased, I have strongly advocated we encourage and support family members staying by the bedside, especially for those patients who have cognitive dysfunction, irrespective of the aetilogy. Many of these patients are monitored by continuous patient observers (CPOs) because they wander or are at high risk of falling. I would like family members to be supported to remain by the patient's bedside by offering them food and drinks, parking and carer certificates. I felt, if we had family members present, we would not need to employ the CPOs, so the overall cost would be neutral. So far, I have been spectacularly unsuccessful in convincing my health service of instituting any change.

I therefore approached my paediatrician colleague to ascertain how they had achieved the universal acceptance of a parent accompanying every child who was admitted to hospital. In our paediatric units there are facilities for parents to stay overnight and sleep by their child's bedside. She referred me to an article printed in the BMJ 17/1/1959 entitled "The Welfare of Children in Hospital" based on a submission from the British Paediatric Association in February 1958. My paediatric colleague was not aware of there ever being a study which examined the outcomes of children admitted without an accompanying parent and comparing them to those with a parent. Nor did she think we could ethically do such a study.

Over the last months of 2023 I have contacted multiple organisations, including the BGS, requesting if they are aware of any study which compares the outcome of those patients with cognitive dysfunction who have a family member by their bedside with those who do not have a family member available. Interestingly, a significant number of organisations have not responded to my request. Those which have, such as the BGS, were not aware of any such studies.

So, I'm left with my experiences, personally and as a geriatrician, that having family members by the bedside has a positive impact on inpatients who have cognitive dysfunction, but has no evidence base from which I can advocate and substantiate this as a strategy my health service could pursue without it likely resulting in increased costs. If anyone can assist me, please do not hesitate to contact me.

Dr Irene Wagner
Consultant Geriatrician, Melbourne, Australia
ijkemper@tpg.com.au

Rethinking anticipatory prescribing: *messages from research*

For the 51% of patients who die at home or in a care home in the UK, obtaining medical assessments, prescriptions and drugs from pharmacies during lengthy overnight and weekend hours can be challenging and at times impossible.

Recognising the problem, National Institute for Health and Care Excellence (NICE) advises prescribing anticipatory medicines as 'early as possible' for people who are likely to need symptom control in the last days of life. But our research at the University of Cambridge shows that anticipatory prescribing (AP) does not always result in timely and effective control of symptoms.

We do not know to what extent AP helps to control symptoms

AP is based on clinicians' perceptions that it offers reassurance and effective, timely symptom relief. But there is inadequate evidence to draw conclusions about clinical effectiveness, cost-effectiveness and safety.

Standardised medications and doses prescribed ahead of need are not always clinically appropriate

It is commonplace to prescribe four standardised medications and dose ranges, often weeks to months ahead of death, with limited review of their continued appropriateness once prescribed.

Not all dying patients need these drugs

Between 40% and 54% of patients prescribed anticipatory prescriptions do not go on to receive any of the medications.

Delays and differing views can affect administration of AP

The time from nurses receiving a family request to administer medication to giving the dose can vary greatly and deciding when to administer medication can cause less experienced nurses considerable unease.

"They [anticipatory medications] were useless because nobody would give him anything." (family carer)

Families and carers are often underinformed about anticipatory medication

AP can be simultaneously reassuring and unsettling, reminding patients and their families of impending death. Discussions with patients and family carers about dying and the role of AP are often vague, inadequate or even absent.

Keeping anticipatory medications in the home may be unacceptable or inappropriate

Putting in place injectable anticipatory medications is not always acceptable for patients and their families, or appropriate where there are concerns about possible drug misuse or diversion.

"I think some patients find it reassuring, other patients I think find it about as reassuring as seeing a coffin propped up in the corner of the room." (GP)

Families carry heavy responsibilities for anticipatory medications

Families carry out considerable work in managing medicines for dying patients, which healthcare professionals rarely see.

Improving symptom control at the end of life: four areas for action

Overall, we suggest that there's a strong case for change. Feedback from practitioners from across the UK supports this. We emphasise that AP is a complex intervention and that making substantive improvements requires system-level changes. We propose the following four areas for action:

1. **Responsive communication between families and healthcare professionals**
   Anticipatory prescribing is an opportunity to hold open, tailored and honest conversations about patients' and families' concerns and the realities of dying, if they indicate that this is their preference, rather than being used as a clinical strategy to keep discussions vague
2. **Responding to changing clinical needs**
   Robust integrated systems such as record-sharing and interdisciplinary meetings are needed to ensure that medications and dose ranges are reviewed regularly and that they are administered when clinically appropriate.
3. **Providing support 24/7**
   Patients and family carers need access to community nursing, community pharmacies and doctor services 24 hours a day, seven days a week.
4. **Listening to the insights of families and carers**
   Community nurses and paramedics require consistent and comprehensive training in the recognition of, and appropriate responses to, end-of-life symptoms and the appropriate administration of anticipatory medications.

This body of research clearly tells us that prescribing of anticipatory medications is not the simple 'fix' in controlling distressing symptoms that we as healthcare professionals often hope it to be. Anticipatory prescribing is a complex and sensitive intervention requiring careful thought, person-centred discussion and regular reviews, often across multiple community providers of care.

Read the full University of Cambridge Research Alert for more information and to see full references: https://tinyurl.com/UCAntMed

Dr Ben Bowers
Primary Care Unit, University of Cambridge

Echoes:

Unravelling communication struggles in dementia

A chance musical outing led Dr Maya Kessler to strike up a conversation with a member of her favourite folk band, resulting in a surprising and thought-provoking discussion about a song based on the experience of dementia.

On an Autumnal evening, I stepped into the Guildhall in Leicester, filled with anticipation to hear Lady Maisery, my favourite folk band. I was expecting their usual repertoire of songs celebrating empowered women, the beauty of nature and old folk tales. Among the expected themes, a captivating piece called *Echoes* cropped up, written and composed by band member Hannah James. It's a beautiful and thought-provoking depiction of a person living with dementia.

I had the opportunity to speak with Hannah via MS Teams, where she shared the inspiration behind the song - her Nana's story. (Hannah and Nana are pictured above). It was a tale that will resonate with many clinicians, a heart-breaking reminder of the challenges faced by those with dementia. In the January of 2021, her Nana entered a residential home after a fall, hip fracture, and post-operative delirium after living with dementia for many years.

The grip of the pandemic forbade family visits, leaving video calls and later, physical visits with a dividing screen, as their only forms of communication. Yet, these attempts to connect only brought distress, leading them to abandon such efforts.

The essence of effective communication with individuals living with dementia underlies every aspect of the song, from the haunting sounds of the accordion to the faint murmuring voices in the background, the carefully crafted lyrics, and the gentle rhythm.
Listening to *Echoes*, I imagined the perspective of a person with dementia desperately trying to communicate with the world around them. The line "Picking up a thread, losing it again" captured a struggle to hold onto moments or conversations that slip away into distraction or memory loss, leaving them to "try another place, try another name."

The breathy sounds of the accordion reflected the distant world they might hear, while the mumbling voices symbolised other residents of the care home lost in their thoughts. "Throwing words against a wall" depicted their desperation to convey a message to caregivers or loved ones, often feeling unheard.

What struck me during our conversation was Hannah's perspective of her song. She was trying to portray the opposite end of the conversation, delving into her and her family's viewpoint. "Picking up a thread, losing it again" symbolised the interactions between her family and Nana, trying various approaches to engage her in conversation.

Similarly, the subtle mumbling she incorporated were representative of her Nana's jumbled words. "Throwing words against a wall" conveyed the sense that their words were not getting through. This added a profound dimension to the song, revealing the experience from both sides - the person with dementia and the caregiver - inviting reflections on their parallel journeys.

Echoes also sheds light on the immense struggles faced by care home residents during the pandemic, affecting both their physical and mental wellbeing. The closing lines of the song, "window eyes reach through the mist, tap the glass and blow a kiss," evoke memories of the scenes we witnessed during COVID, where loved ones were separated by windows. It not only portrayed Hannah's own attempts to communicate through a screen but also symbolised the metaphorical glass wall she felt stood between her and her Nana during their interactions.

> ‘One crucial realisation that emerged is that, as outsiders, we can only observe one side of the challenge in communicating with individuals living with dementia.’

One crucial realisation that emerged is that, as outsiders, we can only observe one side of the challenge in communicating with individuals living with dementia. It has left me pondering the gap between our perceptions and the true experiences of those living with dementia.

Surprisingly, there are very few studies that have looked at communication from the perspective of a person living with dementia. One systematic review[1] found out of 15 studies looking at experiences of communication, only one focused on the person with dementia, while the rest examined the experiences of family members and caregivers. A more recent study, brilliantly titled ‘It’s nice to think somebody’s listening to me instead of saying “oh shut up,”’[2] delved into what constitutes meaningful communication from the perspective of a person living with dementia.

Interestingly, it resonates with some of the themes found in *Echoes* – trying to connect emotionally to each other, feelings of being heard (or not being heard), being physically present to name a few. However, it also emphasises the scarcity of research in this area and the pressing need for evidence-based guidance for family, caregivers, and healthcare professionals.

Echoes serves as a heartfelt reminder of the struggles faced by those with dementia and their caregivers. It underscores the vital importance of person-centred communication, shedding light on the need for greater understanding of our approach to supporting and interacting with individuals living with dementia.

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Spotify users can listen to *Echoes* by scanning the QR code

Dr Maya Kessler
St7 Geriatrics, Royal Derby Hospital

Three minutes with:
Dr Deb Gompertz

BGS's new Deputy Honorary Secretary, Dr Deb Gompertz, shares what she loves about her role as a GP with Extended Responsibilities (GPwER) in Frailty, and why such roles are so valuable to older people.

I have worked as a 'Geri GP' for seven years now, without even realising I *was* one for the first four of those! Since 2020 I have only worked in the frailty/complex care space, working for a Primary Care Network (PCN) looking after an increasingly older, complex population, managing risk, and working across organisations to streamline care.

I have always enjoyed working with and learning from other professionals, and this role enables me to do this across all sectors.

I get to see what services we have in the community to support the population and influence need, looking at all aspects of health in a biopsychosocial model.

Comprehensive assessments, multidisciplinary teams (MDTs), communication and person-centred care are all bog-standard GP work, but difficult to do in the normal 10-minute GP appointment.

The Royal College of General Practitioners (RCGP) is supporting GPs around new and emerging GP roles. The intention is to make alternative roles visible; they are supportive, informational resources offering a benchmark and recommendations for development. It is not rigid but offers guidance around practice. The GPwER in Frailty and Complex Care has been on the College’s website since August 2023 and recognises our role as 'Geri GPs'.

Some highlights for me of the role

- Consultation length isn’t just the 10-minutes we are used to.
- Collaborating with different organisations.
- Compassionate leadership, working with others and developing teams.
- Coaching new and existing teams and individuals.
- Collective responsibility, sharing the risk.
- A 'can do' approach enables team working.

Care, most importantly, is being facilitated and optimised for the people in the communities we work in. It is important we recognise that as General Practitioners we have the skills and local knowledge to do this.

Find out more about GPwER in Frailty by visiting the RCGP website at: www.rcgp.org.uk/your-career/gp-extended-roles/Purpose-of-frailty

The BGS Autumn Meeting 2023 was held on 22-24 November at the Vox in Birmingham, and streamed live online to hundreds viewers. More than 500 delegates joined in person across the three days, at a scenic top-floor setting which overlooked the Pendigo Lake with views across the West Midlands countryside. Close to 600 joined online, contributing via the virtual platform to sessions and discussions in the room, as well as taking advantage of the flexibility of online attendance. As always, the conference sessions were accompanied with a packed social events programme, which offered attendees the opportunity to take part in activities ranging from axe-throwing and archery, right through to bowling and dancing.

Day 1: Community and Primary Care, Orthogeriatrics and Research

The conference was opened by BGS President, Professor Adam Gordon, with an address in which he expressed deep concern about the pressures members and their colleagues are currently experiencing. "It's overwhelming what we're facing at the moment in clinical practice – whether out there in the community or in acute hospitals," he said. "This is a welcome opportunity for us to take a few days away, come together and clear our heads."

The first day kicked off with a packed session on virtual wards and hospital at home initiatives. Dr Shelagh O'Riordan, Consultant Community Geriatrician and Professional Advisor to NHSEI on the Ageing Well Programme, delivered a summary of the national strategy of virtual wards in England. She outlined the formats of virtual ward provision, the key principles, and lessons from implementing services in the South East of England. "I think we can say," she said in conclusion, "that frailty virtual wards, run at scale, can make a significant difference in older people's admissions."

In the panel discussion that followed, the topic of managing risk in virtual wards was up for debate. Shelagh was accompanied by Sarah Mercer, a Consultant Practitioner for Frailty, and Dr Towhid Imam, a Consultant Geriatrician. Highlighting the benefits to older people, Sarah stated that "it's the continuity, the same carers, the same family, the food and drink that you enjoy, your own bed – it's all those things that seem so obvious but make such a big difference." She also credited virtual wards with helping to prevent deconditioning and offering patient choice. Towhid alluded to long ambulance waits and waiting times in A&E, referencing an occasion at his hospital where an older person with frailty had been waiting in an ambulance for 18 hours. "We were able to do all their investigations in the ambulance," he said. "We sent them back to their care home, […] we avoided the admission."

Meanwhile, a separate stream focusing on Orthogeriatrics addressed clinical scenarios such as hip fracture, medications management for falls prevention, and reducing post-operative delirium with neck of femur fractures. Professor Cameron Swift, Emeritus Professor of Medical Gerontology, King's College London, spoke about improvement in hip fracture care and outcomes in older adults. He highlighted the value of evidence, research and audits in driving improvements. Dr Clifford Lisk, Consultant Physician in Acute Medicine and Geriatric Medicine, delivered a presentation on polypharmacy as a risk factor for falls. He discussed the importance of medication reviews and taking a person-centred approach to the prescribing of falls risk increasing drugs (FRIDs). He advocated a multidisciplinary approach to the review of medicines, highlighting tools and resources to support informed decision-making.

As the day continued, the community and primary care stream turned its attention to rehabilitation, with delegates invited to watch ten short case studies of initiatives and services across the UK, ahead of a discussion with those who deliver them. The examples were wide-ranging, from cycling in care homes, to dance, to a lively 'bed disco' where the presenters challenged the audience to hit a beach ball from the front of the theatre to the back, and then return it to the front – a task which had delegates out of their seats and dancing in the gangways (pictured, right). The message behind this was simple – small movements can make a big difference. In the discussion that followed, the vital role of person-centred care in rehabilitation of older people was a common theme. As Kerry Craig, who presented a case study on living well with cancer in older age, summed up: "It's a case of saying 'tell us about what's important to you.' "

Later on, an insightful Town Hall session (pictured left) focusing on care closer to home brought together some of the BGS's multidisciplinary senior officers from across primary and community care. Shelagh O'Riordan and Adam Gordon were joined by Nurses and Allied Health Professionals (AHPs) Council Chair, Consultant Practitioner Dr Esther Clift; Co-Chair of the BGS Community and Primary Care Group, Frailty Lead GP Dr Holly Paris; and BGS President Elect, Professor Jugdeep Dhesi. "I feel the primary care model of care for older people is broken," asserted Holly boldly in her opening words. "We need to rethink how older people use and access primary care, and create the time and space to do the work properly." Approaching the topic from a patient perspective, Esther added "our patients tell us that their top two priorities are staying in their own home and staying independent… [these are] very compelling reasons why community care really matters."

Questions from both the online and in-person audience covered topics such as integration, front door frailty services and managing expectations around acute admission versus receiving appropriate care at home. Highlighting how she would explain to relatives why their loved one is not being treated in hospital, Shelagh said: "It's really powerful to ask somebody what they want, especially if you ask that in front of their relatives, etc… if you ask someone what they want, document what they want and do what they want, you're sorted."

The third stream of the day, which kicked off after lunch, focused on building research capacity. Dr Sanjay Thakrar, Head of Research Policy and Awards, and Oliver Soutar, Grants Manager, both from Dunhill Medical Trust, provided an overview of the Trust's approach to support and capacity building in ageing-related clinical research. Debunking some myths around research funding, Oliver explained that grants are reviewed on merit and not allocated on a random basis, and that adding an eminent researcher's name to your application will not necessarily help it be more successful. On the topic of "fancy acronyms" for research projects, his advice was "if you're spending longer coming up with an acronym for your project than you are on the application, you're probably on the wrong path. Focus on the content – we don't mind a long title!"

A quality improvement session followed, which highlighted some of the top clinical quality abstracts received for this year's meeting. These included presentations on developing a pathway for frail patients referred via colorectal fast-track, and improving end-of-life care in acute medicine.

As the first day drew to a close, Wednesday's social activities included a discussion of the BGS blueprint document, *Joining the Dots: A blueprint for preventing and managing frailty in older people*, hosted by the BGS Nurses and AHPs Council. For delegates with more of an appetite for danger, a visit to the nearby Bear Grylls Adventure provided an opportunity to take on some shooting, archery, axe-throwing and escape rooms.

Day 2: Prescribing, Continence and Research

The second morning started with a stream focused on medicines management, with topics such as oral nutrition, deprescribing attitudes and antimicrobial stewardship. Anne Bentley, Chair of the BGS Pharmacy Group, and Airedale Telemedicine Hub Lead Pharmacist, looked at risks and patient goals when prescribing in community settings, such as care homes. She highlighted triggers for medication review in frailty, such as anticholinergic burden, end of life, falls and transitions of care, but stressing that this should always be fundamentally underpinned by the preferences of the older person. "It absolutely has to centre around the wishes of the patient. That's the important thing – what are we trying to do to help that person?"

Elsewhere at the VOX, in the session on osteoporosis, three presenters from different clinical backgrounds shared their experiences of DXA scanning. Jill Griffin, a radiographer, described the application of DXA scans and how results are interpreted. "It measures the bone mineral content very accurately," she explained. "The measurements are precise and they are reproducible." Dr Nicola Peel, a consultant in metabolic bone medicine, provided some case study examples. Finally, Philippa Russell, a patient who has lived with osteoporosis for more than three decades, detailed her journey since her diagnosis. "Osteoporosis is a bewildering new word for so many folk, and information can point them in the direction of things that can make a difference."

As in previous years, the Association of Academic Geriatric Medicine (AAGM) symposium provided a day-long session focusing on ageing and research. This covered a vast range of studies ranging from dementia, falls prevention and patient involvement. The winner of the 2022 BGS Rising Star Award for Clinical Quality, Dr Towhid Imam, provided an interesting look at the future for frailty, which highlighted the role of integrated care boards (ICBs). Platform presentations included abstracts from Professor Kenneth Rockwood, in which he described the next steps for his renowned frailty index. "I am delighted by the hands that we are in when we look at frailty going forward," he concluded as he reflected on the presentations before him.

The afternoon's Guest Lecture was delivered by Dr Lade Smith CBE, President of the Royal College of Psychiatrists (pictured, above), which looked at ageing and mental health in an unequal world. She highlighted the risk factors for mental health problems, which accumulate as people age. She also highlighted emerging evidence which suggests that people from disadvantaged and minority backgrounds are also at higher risk of mental ill health. "Minoritised ethic populations are among the fastest ageing communities in the UK," she explained. "We already know there's an increased risk due to social disadvantage and perhaps discrimination, and we know that older adults from minoritised ethnic background are under-represented in medical research… there are massive knowledge gaps."

A further highlight of Day 2 was a hands-on continence workshop which offered the opportunity to visit three different practical stations where delegates could test their skills in pelvic examination, incontinence management, and the use of pessaries and continence devices. This multidisciplinary session used anatomical models and authentic continence devices to facilitate realistic demonstration and participation.

For those with energy to spare, the evening's social activities included drinks and canapes with the opportunity to network within their profession, plus bowling, and a sold-out conference dinner at the nearby Genting Hotel.

Day 3: Urgent care, Oncogeriatrics and Workforce

The final day kicked off bright and early with a policy breakfast session for those who hadn't stayed up too late the night before. With a general election highly likely in 2024, the workshop focused on BGS's policy priorities for the next UK government.

The day-long stream on frailty in urgent care settings provided a first look at the new BGS publication on front door frailty (see page 9 for more information). Dr Amy Armstrong, Consultant in Emergency Medicine and Frailty at Edinburgh Royal Infirmary, joined the report's author, Dr Ellie Burn, BGS Front Door Frailty Fellow, to outline how they mapped the UK front-door frailty landscape. "You need to be able to invest time, money and enthusiasm into the process to develop willingness to change a service and a culture," she explained as she highlighted the principles set out in the document. Later on, the morning's sessions also covered outcomes in older trauma and new approaches to frailty in the emergency department.

One of the highlights of Friday's programme was the presentation of the BGS Marjory Warren Lifetime Achievement Award 2023 to Dr Gill Turner, a recently retired geriatrician in the New Forest and former active BGS member. Presenting the award, BGS President Professor Adam Gordon explained how during her career, Gill trained and supported generations of doctors and other medical professionals, inspiring them with her passion for improving the care of older people. The BGS Special Medal 2023 was also awarded to Judith Lund, manager of the British Red Cross team supporting older people across Hull and East Riding. Adam explained to the audience how Judith's passion for helping older people to live fulfilling lives has made her invaluable to the British Red Cross's team of staff and volunteers.

BGS Autumn Meeting 2023: Prize Winners

Best Clinical Quality Platform Presentation

Developing a pathway direct to elderly medicine clinic for frail patients referred via colorectal fast-track: pilot and outcomes

A Nixon; T Memery; J Morgan; A Brown; C Scampion

John Brocklehurst Prize for best clinical quality poster

Advance care planning on the Same Day Emergency Care Older People's Unit: a quality improvement initiative

M Kondo; C Stothard; S Nair; C Handalage; D Gould; J Harris; C Mukokwayarira; T Ferris; A Bowden; L Harrison

Norman Exton-Smith prize for best scientific presentation poster

Development of an innovative digital questionnaire to screen adults for risks of Osteoporosis and Falls by a Primary Care FCP

C Y Birch

Elizabeth Brown Prize for best platform presentation (joint winners)

Association between severe mental illness and risk of osteoporosis and fragility fractures: analysis of UK primary care data

C Avgerinou; K Walters; JC Bazo-Alvarez; RM West; D Osborn; A Clegg; I Petersen

Elizabeth Brown Prize for best platform presentation (joint winners)

Association between severe mental illness and risk of osteoporosis and fragility fractures: analysis of UK primary care data

C Avgerinou; K Walters; JC Bazo-Alvarez; RM West; D Osborn; A Clegg; I Petersen

Eva Huggins prize for best nurse/AHP poster

Protein consumption and determinants in community dwelling older adults: National Diet and Nutrition Survey (NDNS) years 9-11

K Taylor; V Goodwin; S Hope

Best GP Poster prize

Long-term Condition Reviews in General Practice: The Experiences of People with Dementia and their Informal Carers

J Cole; HM Parretti; S Hanson; M Hornberger

Richard Dodds memorial prize

Association of Bradykinin receptor 2 variants with physical performance and muscle mass: findings from the LACE sarcopenia trial

A Shrestha; T Bashir; M Witham; the LACE study group; P Kemp

For upcoming abstract deadlines and submission information, visit www.bgs.org.uk/abstracts

Another highlight of the day was the Trevor Howell Guest Lecture, which this year was delivered by former BGS President, Professor Tahir (Tash) Masud. Tash took the audience through a history of geriatric medicine training, starting with ancient times and finishing with a look at the future. Through his talk, he highlighted how the UK has historically led the way globally in terms of developing its geriatric medicine workforce and services. He also commended the new BGS frailty elearning modules to anyone looking to improve their knowledge around providing healthcare to older people.

The oncogeriatrics stream covered lots of highly relevant topics in cancer care, such as breast cancer, colorectal cancer and gynaecological cancer in older people. The sessions also covered lung cancer clinics, prehabilitation and expanding the workforce in acute settings. A separate workforce stream focused on more specific workforce issues, such as Certificate of Eligibility of Specialist Registration (CESR) applications (now known as Portfolio Pathways), and support for Specialty and Associate Specialist (SAS) Grade doctors.

Throughout the three days of the conference, the UK Covid Inquiry held drop-in sessions to gather evidence for the Every Story Matters element of the inquiry. More than 400 delegates shared their stories, and on the final day, the Every Story Matters team took to the stage to explain in more detail what the inquiry is, how the information is being collected, and what it hopes to achieve. "Covid disproportionately affected older people and it's important for us to remember that, so as geriatric specialists you are best placed to tell the inquiry your observations and about how the pandemic impacted your ability to do your job and care for patients," they explained.

As Friday drew to a close, so too did this year's BGS Autumn Meeting. Adam Gordon closed the conference with a short concluding speech, giving some stats and facts from the three days. "We are heading for a tough winter," he reiterated. "I said on Wednesday that we are here to learn from each other, to partake of each others wisdom, moral support, expertise and kindred spirit. I think that has been evident in all of the rooms and all of the sessions over the last 72 hours." He finished by praising the attendees for all the incredible work they continue to do for older people. "You are a very special bunch of people with very significant skills, knowledge and expertise. Please go back empowered and reinforced about the difference you can make."

BGS Autumn Meeting 2023 @gerisoc

During the BGS Autumn Meeting, 775 healthcare professionals from around the world participated on Twitter/X via the hashtag #BGSconf. In total there were 3,778 posts using the hashtag, which led to 50.86 million impressions globally. Here are some Twitter/X highlights from 22-24 November via #BGSconf...

Holly Paris @Bloody__Holly

@adamgordon1978 delivers opening keynote speech, highlighting the momentum behind our loud advocacy for our older generations voices and the case for more UK systemwide workforce to serve our ageing population #geriatricians #frailty

Bethan Warner @Bethan_Pharm

@jupiterhouse1 tells us about carer overload in hospital@home - whilst family report higher satisfaction, it can be a burden we should be aware of.

Miles Witham @OlderTrialsProf

#deprescribing is a crucial part of falls risk management - Dr Clifford Lisk at #BGSConf. Not always easy or done well in hospitals; why not consider becoming a recruiting site for the @CHARMER_Study to improve practice in this area?

Clare Howard @clarehm123

Just walked into first session of #BGSconf speaker saying "Nice guidance should never trump the patient's wishes" I think I'll be ok 😊

Katy Bettany @KatyBettany

Only 2% of us ask about over the counter medicines - herbal remedies also cause harm. Good learning for me and will change routine practice

Age_and_Ageing @Age_and_Ageing

Another appearance for the difficulties that the NICE head injury guidance poses for services managing older people living with frailty in the community - is it really appropriate to send all of those who are on anticoagulants to hospital reflexively?

Corinne Birch @PhysioCorinne

Clare Howard making the case for deprescribing "In 2023 there were 993,019 people on over 10 meds 16.5% of hospital are due to adverse drug reactions" We need to stop polypharmacy.

British Geriatrics Society @GeriSoc

"You do not go home after a heart attack not on aspirin, you do go home after a hip fracture without bone protection...that stinks" says Johansen 👏 #Orthogeriatrics

Sally Greenbrook @SallyGreenbrook

Is dance an effective rehab tool for older adults? This is the question that @BreatheAHR set out to answer at @GSTTnhs. Answer: yes! One patient decided not to have an evening carer anymore as they could do the tasks on their own now.

Lucy Pollock @lucypgeridoc

Sometimes I think geriatricians are like Ginger Rogers, doing the whole dance backwards, in heels. You have to know all the things you could do for your patient - and work out (together!)

Dr Esther Clift @EstherClift

@WillMcKeown - language around frailty matters- we would NEVER describe someone as 'cancerous' #NAHPCouncil

British Geriatrics Society @GeriSoc

#Geriatricians are often called 'nice' We need slightly sharper elbows as a speciality to influence decision makers and improve health and care for older people" says BGS President Elect @JKDhesi

Adam Gordon @adamgordon1978

@DrLadeSmith, depression and anxiety prevalence maps almost exactly to socioeconomic deprivation - a fairer society is a healthier society.

Dr Alison Cowley @Alison_Cowley

Prof Liz Orton presenting on the FLEXI study. Ensure that implemented interventions are delivered to the right dose and intensity (you wouldn't cut a drug dose shown to be effective so we shouldn't do the same with rehab/falls interventions) 100% agree

Lesley Bull @Drlesleyfish

Final absolute pearl of wisdom from @DrLadeSmith - that's obvious now I've heard it in so many words - often when someone is depressed, even if they don't tell you, you can feel it in the room. Consistent with my experience and something to start actively noticing.

Ben Mearns @BenMearns

The clear message from every #BGSconf is the importance of a strong inter professional team working together with patients and carers! #geriatricsisbrilliant

Huma Naqvi @doc_hnaqvi

Some absolute gems here. 📍Frailty assessment & recognition is vital 📍Definitely collaborative care is the way forward 📍What does the patient wants 📍QOL is approached in an individualised way 📍2 drugs better than 3

Rebecca Talbot @talbot_becky

Great couple of days at the #bgsconf meeting other trainees, sharing issues and learning from each other. Inspiring to see the passion for change to the way we look after older people, with person centred care at the heart of this. #frailty #nicetobenice #brummiebender

ĐulaAlićehajić-Bečić @dula79

@andrew.seaton presenting on antimicrobial stewardship in frailty #BGSconf noted safest prescribing patterns are observed among geri clinicians 1. Recognise sepsis 2. Don't order unnecessary investigations 3. Treat the patient not result 4. Many infections get better without tx.

Joanna Seeley @JoannaHNewman

"The older you are, the longer you stay" Health inequalities in ageing, demonstrated every day in our A&E departments.

Lucy Lewis #ProtectNurse @LucyLew79

So chuffed to be here to see @turner_gill receive her @GeriSoc Marjorie Warren lifetime achievement award. Thank you Gill 🌟

Lesley Bull @Drlesleyfish

Interesting lecture on geriatric medical education from @TashMasud at #BGSconf Agree wholeheartedly more collab and community experience - many GPs have standing offers for hospital docs to come see what we do. Trainees particularly welcome! #primarysecondarycareinterface

British Geriatrics Society @GeriSoc

In 1994 only 8 out of 25 European countries recognised the need for geriatrics as a medical specialty. @TashMasud

HollyParis @Bloody__Holly

Truth: What's the point in screening for frailty in hospitals and communities if you *do* nothing with it... What difference does it make to *your* assessments and decisions? Meaningful change = action #frailty @AmyArmstrongX

Jacqui Holmes @Jacquih0lmes

An insightful few days at #BGSconf in Birmingham, hearing about the latest policies, guidelines, research & resources, reflecting on good practice and considering how we can continue trying to improve healthcare for older people as a multidisciplinary team. Thank you @GeriSoc

Emma @DrEmmaStratton

Thank you to all who organised the #BGSconf an informative, enjoyable and varied programme. I pondered for ages whether to attend in person or not but it's so much better in person. #friends #networking

Amy Henderson-skaif @AmyHSkaif

What a fantastic few days we've had at the BGS Autumn conference. We are all feeling inspired, privileged and passionate in driving change, striving for improving care of older people.

Age_and_Ageing @Age_and_Ageing

@adamgordon1978's closing words: "you are a very special bunch of people with very special skills" - this conference has been an excellent opportunity to encourage and learn from each other, and prepare for the challenges of the approaching winter.

Ben Mearns @BenMearns

Well done @GeriSoc for a wonderful and uplifting #BGSconf conference.

Opinions are divided on NEWS2 in care homes

Care home residents often have complex care needs. When they become rapidly unwell (e.g. with an infection), this is called acute illness or deterioration. In these situations, residents rely on care home staff spotting signs of deteriorating health and working with GPs or community nurses to care for them. However, it is often difficult to know which situations are going to become more serious. Residents are more likely to be taken to hospital when they are unwell, than older adults living in their own home.

The National Early Warning Score (NEWS2) is used to monitor people's condition when they are unwell. NEWS2 aims to identify patients whose condition is likely to deteriorate, making sure that they receive prompt care. The score is based on measuring someone's vital signs e.g. temperature, blood pressure or oxygen levels.

The use of NEWS2 in care homes has increased in recent years. It has been shown to work well among the general population in hospital. But residents' older age, frailty and multiple health problems may make NEWS2 less reliable.

Recently published research showed that for residents admitted as an emergency, NEWS2 can help hospital teams identify those likely to become seriously unwell. However, we do not know if this holds true in care homes, or how residents and carers feel about NEWS2.

NEWS2 in care homes divides opinion. Some think that NEWS2 can help care home and healthcare staff pick up deterioration quickly and communicate effectively together, meaning that residents can be cared for proactively in ways they would like. Others point to unintended consequences, such as care home staff being taken away from other tasks to measure NEWS2. False alarms triggered by NEWS2 could cause unnecessary ambulance calls and emergency transfers to hospital. There are concerns that NEWS2 could be a medical intrusion for residents in their home.

Whichever camp you are in, NEWS2 is already being used widely across UK care homes.

As a GP, I work with care home staff to care for residents when they deteriorate. We all need to consider whether NEWS2 could help us deliver proactive care, in keeping with individual residents' wishes.

Specific questions include:

- For carers, does NEWS2 support carer intuition about how unwell a resident is? Should gut instinct outweigh NEWS2?
- Are care staff comfortable with measuring and acting on NEWS2?
- For residents, does NEWS2 fit with how they would like to be cared for?
- What weight should healthcare professionals give to NEWS2 in decision-making (are individual vital signs more useful)?

Conclusion

As care home and healthcare staff, I believe we should judge if and how to use NEWS2 according to the individual resident and scenario. Using NEWS2 across the board could get in the way of us delivering the right care for residents. NEWS2 is designed to support our instinct of how unwell a person is, not to replace our judgment. It is one piece of the decision-making jigsaw – and is probably a smaller piece for care home residents than for the general population.

Ongoing research will help us understand if and how NEWS2 can improve care for residents. The voices of those who live and work in care homes need to be heard in this research.

Dr Rob Barker
GP, Northumberland; NIHR Applied Research Collaboration (ARC) North East and North Cumbria (NENC) Practice Fellow

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The North Bristol Care Home Interface Project:

A model for delivery of proactive care to care home residents

It is recognised that older people residing in care homes are an underserved population with complex health needs. Studies demonstrate that a high proportion of residents are multimorbid, with over 75% living with dementia and 50% in the last year of life.[1,2]

In 2020, the Enhanced Health in Care Homes (EHCH) model was introduced - designed to place an emphasis on proactive person-centred care. This advises that all new residents receive a holistic review on arrival in a care home, alongside regular structured medication reviews (SMR) and advance care planning (ACP).[3] Despite broad consensus that such reviews are vital for care home residents, the delivery of this can be challenging in the context of a health system under sustained pressures.

In January 2022, North Bristol NHS Trust was awarded Ageing Well funding to create a multidisciplinary team of frailty specialists, from both primary and secondary care backgrounds, to aid delivery of the EHCH model to several pilot care homes. The project aimed to improve quality of care by reducing unwanted or inappropriate hospital admissions and polypharmacy, alongside reducing demand on both primary and secondary care services.

The North Bristol Care Home Interface Project (NCHIP) team comprised GPs with extended roles in frailty and palliative care, consultant geriatricians, a physician associate, a frailty specialist pharmacist, a paramedic frailty practitioner, and a clinical fellow. Pilot care homes were identified through analysis of hospital data, with invitations sent to those with high rates of admissions and deaths in hospital. In addition, local GP practices and the CQC were contacted and invited to put forward care homes in need of extra support.

The team works in an interdisciplinary manner, with all members performing holistic review, and consulting with colleagues in their areas of expertise. Priorities for current and future care are identified through shared decision-making with the resident, care home staff and next of kin. The outputs of the review (prognostication, ACP, and SMR) are documented and actioned directly through the GP system (EMIS) and communicated via email to the care home. ACP is documented using online recommended summary plan for emergency care and treatment (ReSPECT) forms. Through the local 'Connecting Care' platform, these notes are also visible to secondary care and mental health services. The team make onward referrals where appropriate and liaise directly with secondary care specialists for advice should the resident be unable to attend outpatient appointments.

> 'Priorities for current and future care are identified through shared decision-making with the resident, care home staff and next of kin.'

NCHIP reviewed 780 residents across 20 care homes during the six-month pilot. Each resident received SMR, with a total estimated drug acquisition cost saving of £131,462 per annum (an average of £169 per resident) through discontinuation of inappropriate or harmful medications.

New ReSPECT forms were completed for 424 residents. Emphasis was placed on providing guidance regarding admission to hospital from the community, with 270 new forms detailing preferences to avoid hospital admission in all circumstances, save for those where distressing symptoms could not be controlled in the community. Data from the ambulance service were compared for three pilot care homes, demonstrating a 40% reduction in ambulance call outs in the three months following NCHIP review compared to the three months preceding. When the ambulance service attended, there was a 50% reduction in the number of conveyances to hospital.

Multisource qualitative feedback analysis revealed positive themes, such as empowerment of care home staff, reduction in primary care workload, and strengthening the interface. Providing the opportunity for person-centred ACP in a period of stable health was perceived as beneficial to residents, their next of kin, and healthcare professionals alike.

The NCHIP team received five years of substantive funding following the positive pilot results. The project now receives care of the elderly trainees on rotation, widening access to experience in community geriatrics and interface work. At time of writing, 2248 care home residents have been reviewed and over 1,000 new ReSPECT forms created.

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1. Gordon AL, Franklin M, Bradshaw L, Logan P, Elliott R, Gladman JRF. Health status of UK care home residents: A cohort study. Age Ageing. 2014;43(1).
2. Kinley J, Hockley J, Stone L, Dewey M, Hansford P, Stewart R, et al. The provision of care for residents dying in UK nursing care homes. Age Ageing [Internet]. 2014 May 1;43(3):375–9. Available from: https://doi.org/10.1093/ageing/aft158
3. NHS England and NHS Improvement. The Framework for Enhanced Health in Care Homes. 2020 Mar.

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Outcomes in advance care planning:

Putting patients at the heart of their care

‘It appeared pointless to share these important patient-centred discussions in hospital, but not with our community colleagues who were continuing to care for our patients on discharge from hospital’

One small project undertaken in Dorset encouraged older patients and their families to talk honestly about future care wishes, with rewarding results.

80.8% of people over 75 had at least one hospital admission during their last year of life, and at least 96% of these older people had at least one emergency admission, according to Public Health England data published in 2020.[1] On average, 45.6% of people aged 75 years and older died in hospital, even though many people express a wish not to die in hospital. [2]

In 2019 we carried out a small project looking at in hospital treatment escalation plans (TEPs) as a tool to communicate appropriate levels of treatment and how this was shared to wider hospital team. The results demonstrated that TEPs were a useful tool in determining appropriate patient care in hospital. Following on from this we wanted to look at how we could communicate patient wishes around their treatment on their discharge from hospital; it appeared pointless to share these important patient-centred discussions in hospital, but not with our community colleagues who were continuing to care for our patients on discharge from hospital.

What we did

The aim of the project was to use the existing treatment escalation plan and advance care (TEPAC) document available on Graphnet electronic patient record (EPR) to record patient wishes around advance care planning and their future care over a 12 month period, and to review the patients records at 1, 3, 6 and 12 months post discharge to see what had happened to them during this period.

Patients were identified for possible advance care plan (ACP) discussions from their clinical frailty score (7-8; severely frail to very severely frail), presence of life-limiting conditions, multiple co-morbidities and/or evidence of a significant decline in function/cognitive ability.

Following discussion with the patient and their family an ACP was completed. This was then sent home with the patient, emailed to their GP and also to the ambulance service and out of hours service.

The patient’s electronic records were reviewed to establish what had happened during the 12-month period, and we looked for deaths and place of death.

What we found

Our findings are summarised below:

- 155 ACPs were completed over the 12 month collection period – mainly in the Older Peoples Service speciality.
- All patients had a wish to remain out of hospital, be comfortable in their home and not to die in hospital.
- 13 patients sadly died in hospital before discharge.
- 142 patients were discharged with an ACP.
- 116 had died at the 12 month review period.
- Patients who died within 12 months of their initial admission, 93% died out of hospital, compared to the 54.4% national figure.[1]
- 30.9% of patients had a readmission in the 12 month period, compared to the 80.8% national figure.[2]

The benefits

Using the Clinical Failty Scale (CFS) helped us to target those patients who would likely benefit from an ACP discussion as they potentially could be in their last year of life. Patients and families were mostly happy to have discussions and for many it was a relief that the subject had been broached. Many times the feedback from patients and family members was 'thank you, I just didn’t how, or if it was right, to say what we were thinking about future care.'

Families and patients felt empowered to speak truthfully about what they wanted and didn’t want; in fact we actively encouraged them to say what had sometimes been considered by them as unthinkable and certainly not to be said in a hospital setting.

The findings demonstrate that the majority of patient’s wishes for their last year of life were met. All the patients who completed an ACP wished not to be readmitted to hospital and to be kept comfortable at home and to die at home when the time came – patient-centred care in action!

The shared ACP provided community teams with an overview of the patient’s wishes at a time when perhaps patients were not able to actively voice their wishes, allowing community teams to provide appropriate care and support to them in their own home settings when it really mattered.

Future challenges

Sharing hospital documentation among community colleagues remains problematic due to the many different systems that are used and lack of links between them. This small project has highlighted how important, but also how difficult, it is to share ACP discussions between all care settings and as a result a new advance care plan document has been designed which once completed with be electronically sent to the patient’s GP, making the communication process simpler and quicker.

Finally with the continued pressure on hospital beds and an ever ageing population, ACP discussions have never been so important and reminds us all that the patient should be at the center of all our care and decisions.

ACPs were completed in 2020 and the follow-up data collected in 2020-2021. The aim is to repeat the project using the new ACP and compare the findings.

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BGS responds to long-awaited publication of proactive care guidance

The BGS was pleased to see that the long-awaited guidance on proactive care, *Providing care and support for people living at home with moderate or severe frailty*, was published by NHS England on 19 December.

NHS England

Proactive care: Providing care and support for people living at home with moderate or severe frailty

Previously known as anticipatory care, proactive care is one of the three original streams of the Ageing Well programme, as detailed in the NHS Long Term Plan, published in January 2019. The other two streams of the Ageing Well programme, Enhanced Health in Care Homes and Urgent Community Response, have both been fully rolled out across England. However, anticipatory/proactive care has been beleaguered with delays and funding problems.

Proactive care is a vital part of helping to delay frailty and maintain older people’s independence. BGS members tell us how important it is to act early rather than waiting until older people are in need of urgent or emergency care.

We welcome the focus of this guidance on people living at home with moderate or severe frailty, for whom the right support from health and social care professionals, voluntary sector agencies and neighbourhood teams can help to delay further development of their frailty. Frailty affects 1 in 10 over the age of 65 and up to half of the population over 85 and it is these groups who are most likely to benefit from proactive care. Many people with frailty will also be living with other long-term conditions, which makes the focus on providing holistic assessment in this guidance very welcome.

However, we remain disappointed that the initial promised funding for this work was cut and has not been reinstated. Integrated Care Systems (ICSs) are struggling with the many commitments they are required to fund. As the recent report from the Chief Medical Officer pointed out, maximising the health and life chances of older people should be considered a national priority. Upstream action to support healthy ageing and proactive care for frailty should be part of the Government’s overall public health strategy with additional funding provided. We urge the Government to allocate funding to allow systems to roll out proactive care. Effective implementation of proactive care will save the NHS money in the long term as it will help older people to remain well without needing costly hospital care.

You can read our response in full at https://www.bgs.org.uk/NHSEproactivecare

Advocacy for all: Supporting older people to live happier lives

For over 20 years OPAAL (The Older People's Advocacy Alliance) have worked to promote and develop independent advocacy services for older people, and those who support them, in whatever way they engage with older people.

We encourage everyone, ranging from older individuals and their families and friends to professionals dealing with older people to learn about the power of independent advocacy, so that the benefits for older people of living in a way that makes them happy, safe, and fulfilled are delivered in their own networks and communities.

As a membership organisation, we are proud to champion the fantastic work undertaken by those members who are working towards ensuring older people's needs, wants and rights are protected and promoted. Our role includes campaigning on behalf of our members, supporting them with resources, building partnerships and sharing good practice in our community. We are well known and highly regarded in the advocacy sector with a long history of successful partnership working and expert referrals.

For members of the public we provide free support, research, and signposting on ANY issue that they are struggling to find a way to speak up for themselves. Our success rate in resolving issues as diverse as finding mobility support, to stress caused over financial issues with family members, is currently running at 85%. Our bespoke service is delivered in a timely manner. We frequently hear that we are the only organisation an older person has contacted that rings them back when we say we will.

We also provide a range of free resources, which we call advocacy checklists, which enable an older person to prepare for and execute, better conversations about important decisions in their lives. These checklists can be used by a person by themselves or with a trusted supporter. The current topics include:

- Effective communication with health care providers
- Considering a change in living conditions
- Choosing someone to act as a Lasting Power of Attorney
- Making a complaint about rented accommodation
- Considering Advanced Decisions
- Asking for mobility or dementia related adjustments to be made to a home
- Wanting to make a complaint
- Asking for energy saving adjustments to be made to a home
- Asking for a medical second opinion
- Asking for an overall assessment of living conditions
- Choosing someone to act as an informal advocate
- Needing to move house or into a care facility.

Through advocacy support, people can be empowered to speak up for themselves, particularly when they are going through stressful situations or experiencing difficulties accessing support.

OPAAL are the only UK organisation devoted to supporting older people's advocacy in this way, and who is committed to providing support and signposting on any issue that a member of the public brings to our attention – as far as we possibly can.

We find that many older people are finding it difficult to navigate complex telephone systems and digital contact arrangements. Our Operations Lead undertakes much of this challenging work for the person, and we have found that support from a professional organisation ensures that when the individual then takes over the matter for themselves, they are far better received by service providers once we have made it known that this older person has OPAAL's backing.

Even when we are unable to help an individual, the feedback we receive is that the older person is far happier and accepting of the outcome, as we do exactly what we say we will, by emailing and contacting them whenever we say we will. This leads to the older person feeling respected and heard.

Of the enquiries we have received, 35% relate to housing issues; 20% relate to homelessness; and 20% relate to debt problems where other agencies have been approached and the older person has been unable to make themselves heard. Our resolution rate is currently running at 85%. We would like to increase the speed at which we can resolve these issues for older people, thereby reducing their stress and anxiety as quickly as possible.

We already keep detailed information on the number of enquiries undertaken, the steps we take, the outcomes and service user feedback. We will continue to do so.

OPAAL will use the data collected to produce new products/campaigns to match the trends in issues older people are identifying according to our data. It should be noted that although we are based in the Midlands, our work is operated throughout the country and we try and help everyone who contacts us.

Sharon Jenkins
Operations Lead, OPAAL

Find out more

If anyone would like to become a member of OPAAL or find out more about the organisation, please contact Sharon Jenkins on sharon.jenkins@opaal.org.uk

BGS vacancies and notices

View all current BGS opportunities online at **www.bgs.org.uk/BGSvacancies**

SPREAD THE WORD:

Many BGS members are now eligible to apply for a FREE place at our upcoming meetings. There are limited spaces to attend either in person or online. Find out more at **www.bgs.org.uk/grants**

Upcoming abstract submission deadlines

- **Northern Ireland and Royal College of Psychiatrists Old Age Faculty Joint Meeting**
  Deadline: 2 February
- **Movement Disorders Meeting 2024**
  Deadline: 19 January
- **BGS Spring Meeting 2024**
  Deadline: 16 February
- **Scotland Spring Meeting 2024**
  Deadline: 1 March
- **Wales Spring Meeting 2024**
  Deadline: 1 March
- **POPS Meeting (Perioperative Care of Older People Undergoing Surgery)**
  Deadline: 3 June
- **Cardiovascular Health of Older People 2024**
  Deadline: 3 June
- **BGS Autumn Meeting 2024**
  Deadline: 29 July

Upcoming BGS events

- **Applying for Internal Medical Training Posts**
  24 January 2024 (4.00-5.30pm) - FREE webinar
- **Improving Education of the 3 D's – Dementia, Delirium and Depression**
  5 February 2024 (1.00-2.30pm) - FREE webinar
- **Yorkshire and Northern Region Spring Meeting 2024**
  6 February 2024 - Online
- **South East and South West Thames Region Spring Meeting 2024**
  22 February 2024 - Online
- **CGA in Primary Care**
  28 February 2024 (1.00-2.30pm) - FREE webinar
- **Northern Ireland and Royal College of Psychiatrists Old Age Faculty Joint Meeting**
  1 March 2024 - Belfast
- **Wessex and South West Region Spring Meeting 2024**
  8 March 2024 - Location TBC

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www.bgs.org.uk/Spring24