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www.hospiceuk.org
WELCOME TO CLINICAL ECHO June 2022
June 8, 2022

Hope for the future?

Evidence Update
Max Watson

APM Update
Matt Dore

Special Rules benefits for people with a terminal illness Dr. Emily Pikett DWP

Nurse and AHP Palliative Career development Vanessa Taylor University of Central Lancashire

The role of Hospice services across the UK HUK and Nuffield Trust Dominic Carter HUK

Chat Box
• Your Questions
• Resources
• Information /innovations
• Email clinical@hospiceuk.org

Please share resources, powerpoint, links etc with those who would benefit
Health and Care Bill 2022
Palliative Care Mandate
Chat BOX

1. Every setting
2. 24/7 to palliative care beds
3. 24/7 palliative care advice and support for professionals
4. 24/7 palliative care advice for patients and carers
5. Readily available supply of the key medications, equipment and staff
6. Systems to share key information across the key stakeholders
7. Promotion and recording of what matters most conversations
8. Ongoing, QI and research to ensure that services are innovative and responsive to changing needs and evidence

Examples to set before the ICBs?

Email in chat please
5th June, 2022

Last Month 44,000 deaths (73,000)
14 million cases (18 million)
England: 1.6% of the population had coronavirus in week ending 21 May 2022.

Wales: 1.74% of the population had coronavirus in week ending 21 May 2022.

Scotland: 2.57% of the population had coronavirus in week ending 21 May 2022.

Northern Ireland: 1.27% of the population had coronavirus in week ending 21 May 2022.

UK: deaths involving Covid-19
Covid-19 was involved in the deaths of 24 people in the UK on 20 May 2022, in most recent ONS data available.

Source: ONS - provisional daily death registrations involving Covid-19, by date of occurrence.

UK: people in hospital with coronavirus each day
5,584
Who is - and isn't - vaccinated?

Bar label shows percentage of age group with no vaccine or one dose only

- No vaccine
- First dose only
- Two doses
- Three doses

Vaccination status in England. Data: data.gov.uk, correct as of 31 May, 2022. NB: it takes two weeks for each dose to become effective.
Reinfections as a percentage of daily new cases in England. Case only logged as a reinfection if person had a registered positive test 90 days prior to testing positive again. Data: data.gov.uk, updated 26 May, 2022.
Clinical

Contact tracing

Contact tracing helps prevent the spread of coronavirus (COVID-19).
The app will send you an alert if you have been in close contact with someone who has tested positive for the virus.

To enable Contact Tracing for this app you need to allow ‘Exposure Notifications’.
The COVID-19 Pandemic, Stress, and Trauma in the Disability Community: A Call to Action

Emily M. Lund
University of Alabama

Anjali J. Forber-Pratt
Vanderbilt University

Catherine Wilson
Tampa, Florida

Linda R. Mona
VA Long Beach Healthcare System, Long Beach, California

**Purpose:** To inform the field of rehabilitation psychology about the impacts of the 2019 novel coronavirus (COVID-19) on the disability community in the United States and the additional sources of stress and trauma disabled people face during these times. **Method:** A review of the literature on disability and COVID-19 is provided, with an emphasis on sources of trauma and stress that disproportionately impact the disability community and the ways in which disability intersects with other marginalized identities in the context of trauma and the pandemic. We also reflect on the potential impacts on the field of psychology and the ways in which psychologists, led by rehabilitation psychologists, can support disabled clients and the broader disability community at both the individual client and systemic levels. **Results:** The COVID-19 pandemic introduces unique potential sources of trauma and stress within the disability community, including concerns about health care rationing and ableism in health care, isolation, and the deaths and illnesses of loved ones and community members. **Conclusions/Implications:** Rehabilitation psychologists and other professionals should be aware of the potential for trauma and stress among disabled clients and work with them to mitigate its effects. Additionally, psychologists should also work with the disability community and disabled colleagues to address systemic and institutional ableism and its intersections with other forms of oppression.

Abelism in the Pandemic
The pandemic has been a brutal reminder that disabled people don’t matter. Living through this, as a disabled person with a wonky immune system, has been a reminder that my life doesn’t matter to most.

Where I do matter is in my disability community, the community of folks at such risk of this deadly disease who have rallied and worked together to protect ourselves. After two years of the pandemic, of the lockdowns, of the forgetting and the ignoring and the gut-wrenching fear, my nerves are sanded raw, jangling now at the slightest breeze of change. A new variant is announced, restrictions for me creep back in, and I’m left to wonder if this is how it will be from now on. No more music, no more crowds, no more indoor anything really, and no more footy. For the rest of my life.

Sleepio to treat insomnia and insomnia symptoms

1 Recommendations

1.1 Sleepio is recommended as a cost saving option for treating insomnia and insomnia symptoms in primary care for people who would otherwise be offered sleep hygiene or sleeping pills.

1.2 For people who may be at higher risk of other sleep disorder conditions, such as in pregnancy, or in people with comorbidities, a medical assessment should be done before referral to Sleepio.

1.3 More research or data collection is recommended on Sleepio for people who are eligible for face-to-face cognitive behavioural therapy for insomnia (CBT-I) in primary care. This is because there is limited clinical evidence to show how effective Sleepio is compared with face-to-face CBT-I. Find out more in the further research section.
Post Covid Syndrome
1. Reports even mild Covid 19 infection having neurological and mental health sequelae.

2. Close links infection, inflammation, cytokine impact on BBB, on mood, and brain protein housekeeping.

3. Viral infection in nose, via olfactory bulb can trigger neuro inflammation and degeneration.??

4. Implications of mouse studies for second pandemic of Parkinson's, Alzheimer's UNCERTAIN.
POST-COVID SMELL AND TASTE DISORDERS

- ANOSMIA – COMPLETE LOSS OF SMELL
- HYPOSMIA – DECREASED SENSE OF SMELL
- PAROSMIA – ALTERED SENSE OF SMELL (FAMILIAR ODORS SMELL “WRONG”)
- PHANTOSMIA – DETECTING A PHANTOM SCENT WHEN NONE IS PRESENT
- DYOSOMIA – DISTORTED SENSE OF SMELL, INCLUDING PAROSMIA AND/OR PHANTOSMIA
- DYSGEUSIA – ALTERED SENSE OF TASTE, OFTEN RESULTING IN PERCEPTION THAT FOODS TASTE SOUR, METALLIC OR ROTTEN
PAROSMIA: TAKES ITS OWN TIME

- Some people experience parosmia after Covid
- One of many potential symptoms of long-haul Covid infection
- Global study says 70% of parosmia patients under-30, 73.5% girls
- Covid damages receptors, nerves involved with sense of smell
- Damage repairs with time, but may cause disruption in how we perceive odours
Parosmia post COVID-19: an unpleasant manifestation of long COVID syndrome

As we begin to slowly unravel the mystery hidden behind the current pandemic, novel clinical manifestations are emerging ceaselessly following SARS-CoV-2. Olfactory dysfunction, which has become one of the sough-after clinical features of COVID-19, has been associated with less severe disease manifestation.1 Yet, the previously deemed ‘fortunate’ patients with olfactory dysfunction who successfully recovered from COVID-19 are being afflicted by another sinister condition known as parosmia, which is found to be more debilitating than loss of smell.

Parosmia or distortion of smell is currently regarded as an early sign of the long COVID-19 syndrome or chronic COVID-19 syndrome. Carfi et al found that 87.4% of patients in their study who recovered from COVID-19 had at least one persistent symptom with loss of smell among them.2 However, recent reports have discovered that a number of patients with loss of smell or anosmia regained their smell, yet surprisingly this time, the smell was distorted. The magical aroma of coffee had turned into a nightmare as coffee began to smell pungent like gasoline and favourite dishes were turning to smell more like rotten food or garbage, which inadvertently affects taste as food becomes almost unpalatable.

The word parosmia is taken from the Greek words: para (amiss) and osumi (smell) which is defined as a distortion of smell with the presence of odorant, whereas phantosmia is a condition where there is a distortion of smell with the absence of odorant.3 In the majority of patients who previously to occur in a patch, checkerboard manner, thus leading to distortion of smell or parosmia. This information appears to alter Mozell’s theory of spatiotemporal pattern of response to magnitude and latency differences across the mucosa to odorants whereby human nose was supposed to separate vapour or odorant in a similar pattern to a gas chromatograph.4

Although parosmia following recovery from postetorial olfactory loss has long been reported,5 in patients recovering from COVID-19 it must be a distressing situation. Having said that, the bright side of parosmia is that it denotes gradual recovery of smell function. Parosmia has been reported to be associated with spontaneous olfactory recovery suggesting positive clinical outcome.6 Although stiff in infancy, promising reports on the outcome of olfactory retraining therapy for patients with parosmia post COVID-19 are rising. Olfactory retraining therapy aims to strengthen olfactory training.

To cite Parasomnia J, Narayanan P. Postgrad Med J 2021; 2022: 98; e96.

When the early phase of illness is associated with loss of smell, parosmia is a late onset symptom in the majority of patients who report it, developing on average three months after infection.

Practical tips on living with parosmia, developed by clinical advisors and contributors (from AbsSent https://absent.org/)

Get to know your trigger foods and “safe” foods. Room temperature or cold food will give off cold odour and will be easier to eat.

Parosmia can fluctuate. Some days will be worse than others. Keep a diary and continuing to try things periodically—..

Some people find that “pushing through” the unpleasant taste in food is a way to make things improve. This may not be possible in the early stages of parosmia if nausea is a problem, but as time goes on it can be helpful.

We are hearing recovery stories even after 21 months. There is no hard and fast timeline for recovery.
Virus
Monkeypox: What do we know about the outbreaks in Europe and North America?

Monkeypox, a virus first discovered in monkeys in 1958 and that spread to humans in 1970, is now being seen in small but rising numbers in Western Europe and North America. Elisabeth Mahase summarises what we know so far.

Elisabeth Mahase

How many cases have been confirmed?

Case numbers seem to be rising daily though are still low. In England 20 cases were confirmed between 6 and 13 May. Meanwhile, Spain has reported 33 potential but unconfirmed cases, and Portugal has confirmed five of its 20 suspected cases. One case in the US has been confirmed.1

How is it spreading?

Transmission between people mostly occurs through large respiratory droplets, normally meaning prolonged face-to-face contact. But the virus can also spread through bodily fluids. The latest cases have mainly been among men who have sex with men. The UK Health Security Agency said that although monkeypox has not previously been described as a sexually transmitted infection, it can be passed on by direct contact during sex. It can also be passed on through other close contact with a person who has monkeypox or contact with clothing or linens used by a person who has monkeypox.2

Inger Damin, director of the US Centers for Disease Control and Prevention’s Division of High Consequence Pathogens and Pathology, said, “Many of these global reports of monkeypox cases are occurring within sexual networks. However, healthcare providers should be alert to any rash that has features typical of monkeypox. We’re asking the public to contact their healthcare provider if they have a new rash and are concerned about monkeypox.”

What are the symptoms?

Symptoms can include fever, headache, muscle aches, backache, swollen lymph nodes, chills, and exhaustion. Typically a rash will develop, which often starts on the face but can then spread to other areas of the body. The rash will go through different stages before forming a scab that finally falls off. The European Centre for Disease Prevention and Control (ECDC) said that the recent cases among men who have sex with men.

Seven previous cases of monkeypox have been reported in the UK (in 2018, 2019, and 2021), mainly among people with a history of travel to endemic countries. However, the ECDC has said that this latest outbreak is the first time that chains of transmission have been reported in Europe without known epidemiological links to West and central Africa, and they are also the first cases reported among men who have sex with men.

In a statement it said, “Given the unusually high frequency of human-to-human transmission observed in this event, and the probable community transmission without history of travelling to endemic areas, the likelihood of further spread of the virus through close contact, for example during sexual activities, is considered to be high. The likelihood of transmission between individuals without close contact is considered to be low.”

Correction: On 20 May we updated the number of confirmed cases in England from nine to 20.

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Signs and Symptoms

The incubation period for monkeypox is usually 7-14 days but can range from 5 to 21 days. The rash typically develops 1-3 days after the onset of fever, often beginning on the face/mouth and spreading rapidly to the rest of the body, including the palms and soles. The rash appears similar to that of chickenpox. Monkeypox lesions tend to progress through macular, papular, vesicular, and pustular stages before resolution. The illness occurs for 2-4 weeks, with some patients having ulcerative lesions.
Evaluation

When evaluating a patient with suspected monkeypox, droplet precautions should include PPE, such as an N95 mask, gown, gloves, and eye protection. Conduct a travel and exposure history: When confirmed, maintain a log of all clinical teammates that have had patient exposure. Appropriately disinfect patient room surfaces after the patient departs.

Treatment

Treatment for monkeypox infection is largely supportive and symptomatic. It is crucial to isolate patients and take appropriate precautions to prevent spread of the disease. The patient is contagious until all scabs have dried and fallen off. Monkeypox vaccines are available, and vaccination after high-risk exposure has been shown to prevent disease or mitigate severity in some cases.[9]

No smallpox vaccines are authorized for use against monkeypox, however the third-generation smallpox vaccine Imvanex (Modified Vaccinia Ankara) has been authorized by the European Medicines Agency (EMA) for the EU market against smallpox and has demonstrated to provide protection in primates.
In a new risk-assessment document, the European Centre for Disease Prevention and Control (ECDC) summarizes what we currently know about monkeypox and recommends that European countries focus on the identification and management of the disease as well as contact tracing and prompt reporting of new cases of the virus.

Recent Developments

From May 15 to May 23, in eight European Union (EU) member states (Belgium, France, Germany, Italy, the Netherlands, Portugal, Spain, and Sweden), a total of 85 cases of monkeypox were reported; they were acquired through autochthonous transmission. The latest diagnosed cases of monkeypox have mainly been recorded in men who have sexual relations with other men, suggesting that transmission may occur during sexual intercourse, through infectious material coming into contact with mucous or damaged skin, or via large respiratory droplets during prolonged face-to-face contact.

Andreas Ammen, MD, director of the ECDC, stated that “most current cases have presented with mild symptoms of the disease, and for the general population, the chance of diffusion is very low. However, the likelihood of a further spread of the virus through close contact, for example during sexual activities among people with multiple sexual partners, is considerably increased.”

Stella Kyriakides, European commissioner for health and food safety, added, “I am worried about the increase of cases of monkeypox in the EU and worldwide. We are currently monitoring the situation and, although, at the moment, the probability of it spreading to the general population is low, the situation is evolving. We should all remain alert, making sure that contact tracing and a sufficient diagnostic capacity are in place and guarantee that vaccines and antiviral drugs are available, as well as sufficient personal protective equipment (PPE) for healthcare professionals.”

Routes of Transmission

Monkeypox is not easily spread among people. Person-to-person transmission occurs through close contact with infectious material, coming from skin lesions of an infected person, through air droplets in the case of prolonged face-to-face contact, and through fomites. So far, diagnosed cases suggest that transmission can occur through sexual intercourse.

The incubation period is 5–21 days, and patients are symptomatic for 2–4 weeks. According to the ECDC, the likelihood of this infection spreading is increased among people who have more than one sexual partner. Additionally, people with severe disease in some groups (such as young children, pregnant women, and immunosuppressed people). However, the probability of severe disease cannot yet be estimated precisely.

The overall risk is considered moderate for people who have multiple sexual partners and low for the general population.

Clinical Course

The disease initially presents with fever, myalgia, fatigue, and headache. Within 3 days of the onset of the prodromal symptoms, a centrifugal maculopapular rash appears on the site of primary infection and rapidly spreads to other parts of the body. The palms of the hands and bottoms of the feet are involved in cases where the rash has spread, which is a characteristic of the disease. Usually within 12 days, the lesions progress, simultaneously changing from macules to papules, blisters, pustules, and scabs before falling off. The lesions may have a central depression and be extremely itchy.

If the patient scratches them, a secondary bacterial infection may take hold (for which treatment with oral antibiotics is indicated). Lesions may also be present in the oral or ocular mucous membrane. Either before or at the same time as onset of the rash, patients may experience swelling of the lymph nodes, which usually is not seen with smallpox or chickenpox.

The onset of the rash is considered the start of the infectious period; however, people with prodromal symptoms may also transmit the virus.

Most cases in people present with mild or moderate symptoms. Complications seen in endemic countries include encephalitis, secondary bacterial skin infections, dehydration, conjunctivitis, keratitis, and pneumonia. The death rate ranges from 0% to 11% in endemic areas, with fatalities from the disease mostly occurring in younger children.

There is not a lot of information available on the disease in immunosuppressed individuals. Patients with a concomitant HIV infection present with more severe disease, with a more rapid progression to the disseminated stage. Patients with a concomitant HIV infection may present with ulcerative lesions that are painful and may extend to the lymphatic system.

Sequelae from the disease are usually disfiguring scars and permanent corneal lesions.

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Vaccine
COVID-19

How are vaccines being adapted to meet the changing face of SARS-CoV-2?

The vaccines’ development was a miracle of modern science—but as SARS-CoV-2 adapts, how are manufacturers and researchers responding? Chris Stokel-Walker learns more

Chris Stokel-Walker freelance journalist

It seems like a lifetime ago, but the first clinically approved vaccine against SARS-CoV-2 was given to a patient just 17 months ago, on 8 December 2020. Since that first vaccine dose, developed by the drug company Pfizer, a number of vaccines have been developed. Ten are approved by the World Health Organization, and scores more are still undergoing trials.

However, just as vaccine development hasn’t stood still, neither has the virus itself. The changing face of the novel coronavirus has challenged scientists to modify existing vaccines to better tackle the changing characteristics of SARS-CoV-2. Yet, despite much talk of modified vaccines for variants, the world is still using largely the same original vaccines for initial rollouts and booster doses.

“It seems as if the dominant things I’m hearing about at the moment are updates to existing vaccines,” says Paul Bieniasz, virologist at the Rockefeller University, New York. Those updates modify how a vaccine works to make it better match the circulating strains of SARS-CoV-2 around the world, much like the existing system for vaccinating against influenza (see below). National and international groups analyse which strains are circulating worldwide and then decide strains are the most likely to require updates to existing vaccines.

A key question at this phase of the covid pandemic is whether it’s better to continue playing catch-up with the virus and its variants or to try to develop multivalent vaccines, based on a mixture of strains that could prime the immune system against potential future variants. “We haven’t yet got a consensus agreement on what strains manufacturers should put in their vaccines,” says Penny Ward, visiting professor in pharmaceutical medicine at King’s College, London. “In part, that’s because of the rather rapid emergence of novel strains of this virus, and the fact we’re learning about the disease it causes as we go along.”

What modified or updated covid vaccines are in development?

Many of the original main vaccines against SARS-CoV-2 are the subject of ongoing clinical trials looking at the immune response to different variants, says Ward. Not many findings have been publicly released, but Moderna released a preprint paper in April looking at a modified vaccine variant raised against the spike protein of the beta variant.1

Reassuringly, “it showed a superior immune response when they use the variant vaccine in an already immunised population,” says Ward.

Some more experimental vaccines in development aim to invoke a broader immune response—not just to variants we’ve encountered so far or could see in the near future, says Bieniasz, but to sarbecoviruses, the group of viruses that gave rise to SARS-CoV-2 and the original SARS-CoV. One early trial, which began in September 2021, has reported promising initial results from a multivalent vaccine, albeit one that triggers the production of neutralising antibodies at a similar rate to approved mRNA vaccines.

The most widely used of these experimental approaches is based on nanoparticles that contain mixtures of parts of the spike protein from various sarbecoviruses. “It’s somewhat clear these vaccines can induce a broader antibody response that would give broader protection,” says Bieniasz. One such drug, developed by researchers at the University of Cambridge, entered clinical trials in December 2021.3

How do these approaches compare to the adaptation of flu vaccines each year?

The first bivalent flu vaccine, which can neutralise the effects of influenza types A and B, has its 80th birthday this year. But the key difference with SARS-CoV-2 is time, says Ward. She explains, “We’re not in the same position we’re at with the flu vaccines, where there are two yearly updates of the vaccines; one for the southern hemisphere and one for the northern hemisphere seasons, based on the types that have been circulating the preceding seasons.”

Although flu also adapts and spreads significantly, SARS-CoV-2 does so while being a relatively unknown quantity. “With the omicron variant, within three months, pretty much everybody on the planet has had the infection, whether or not you’ve been vaccinated,” says Paul Hunter, professor of medicine at the University of East Anglia. “The value in developing new variant vaccines is always mitigated against the time taken to find a new variant, figure out if it’s an important one, and then develop, modify the vaccine, check it’s worked, and approve.”

With SARS-CoV-2 the emergence and spread of new variants globally and whatever the season—has been frighteningly fast.
WORKFORCE
Together for Short Lives' new research carried out with children's hospices in England has revealed:

- The average vacancy rate for nurses and other non-medical care and support professionals working at the equivalent of NHS Agenda for Change bands 5-9 inclusive has grown to 18.6% in 2022, compared to 12.2% in 2019, 11% in 2016 and 10% in 2015.
- This is higher than the NHS nursing vacancy rate in England in quarter three of 2021/22, which was 10.5%.
- Within this, one in four (26%) band 5 posts in children's hospices are vacant.
- Over two thirds (70%) of children's hospices report higher care and support professional vacancy rates compared to April 2019.
- Among those children's hospices who are experiencing a higher vacancy rate, over half (58%) say that this has led to them cutting or stopping their short breaks for respite for families of seriously ill children.
- Almost all (93%) cite a lack of professionals with the skills and experience to recruit as a significant or very significant factor in explaining their care professional vacancy rate. 89% cite competition from other local healthcare providers as significant or very significant. 78% state that the fact that children's palliative care is a challenging field to recruit to as a significant or very significant factor.
**Results.** Eighty-one responses to the survey were returned (54% response rate); 59 were complete of which 47 contained COVID-19 data. Findings indicated that COVID-19 impacted on out-of-hours community-based palliative care. To meet increased patient need, hospices reconfigured services; redeployed staff; and introduced new policies and procedures to minimize virus transmission. Lack of integration between charitably and state funded palliative care providers was reported. The interconnected issues of the use and availability of Personal Protective Equipment ($n = 21$) and infection control screening ($n = 12$) resulted in changes in nursing practices due to fear of contagion for patients, carers and staff.

**Conclusions.** Increased demand for community palliative care services, hospices rapidly adapted and reconfigure services. Even though led to some service improvements, in the main, out-of-hours service reconfiguration resulted in challenges for hospices, including workforce issues, and availability of resources such as Personal Protective Equipment. These challenges were exacerbated by lack of integration with wider healthcare services.
We have seen some excellent examples of good practice from outreach work and joint MDTs for child health, to population-based approaches to management of chronic disease, and partnership working on end-of-life care. All these were characterised by strong relationships, trust and mutual understanding between primary and secondary care clinicians.

Capacity and organisational development support for changing clinical models must be identified as part of the implementation of these new teams, supported by practical tools such as job planning and e-rostering across the whole workforce.
1. End of life care, old age care and rehabilitation services combined

2. Focus on well coordinated community services

3. Staff work across both hospital and community sites

4. Paperwork kept to an absolute minimum in comparison with UK

5. Single Governance Model
“20 in the last week…”
Equitable Care for All Ethnicities Audit

Why are we doing this?
The COVID-19 pandemic has demonstrated the importance of ethnicity data in monitoring racial and ethnic inequalities. Good quality ethnicity data is consistent, complete and the recorded ethnic group should be self-determined. When recorded data is poor quality, rigorous research is challenging and we are not able to assess inequitable delivery of healthcare. Valid and consistent data can be used to demonstrate the extent, nature and impact of ethnic inequalities in society and improve services.

What do we want to do?
We aim to conduct a UK wide audit (led by King’s College Hospital). We aim to investigate the validity and consistency of recorded ethnicity groups across palliative care relevant UK health databases using patient self-definition. We will use this audit to inform development of an intervention to improve ethnicity data collection in the future.

How will we do this?
We will recruit audit sites from palliative centres (hospitals, hospices and community teams) across UK who will participate in a one day audit during a two week period (13/06/22-24/06/22). We will assess validity of recorded ethnic group by comparing patient self-defined ethnic group (collected directly from patients on day of audit) with ethnic group recorded in healthcare databases (collected from databases on day of audit). All data will be collected anonymously centrally at King’s College Hospital for analyses. On analyses, sites and individual patients will not be identifiable.

We would like to take part, who should we contact?
If your service would like to take part in this important audit, please email to express your interest to Gemma Clarke g.c.clarke@leeds.ac.uk

Audit Team:
Dr Sabrina Bajwah & Dr Gemma Clarke (joint Leads)
Dr Jamilla Hussain
Dr Zoobia Islam
Professor Jonathan Koffman
Dr Catriona Mayland
Dr Matthew Alison

51 Sites Signed up already!
PALLIATIVE CARE RESEARCH
‘To offer optimal individualised palliative care to patients and their families, research findings need to be integrated with our individual clinical expertise. This is important for patients and families, and we must strive to get it right’

There is a growing field of palliative care publications and that a large proportion focuses on symptoms and their management

‘The challenge is translating the knowledge from the best empirical evidence, to ensure our clinical practice is always informed about the potential benefits and harms associated with treatments, so high-quality patient care is maximised.’
• Once we are aware of the evidence, there is variability in how this influences what we do

• If the evidence does not confirm our implicit and explicit bias, we may not integrate it into our practice.

• Implementation also differs between us, and this depends on if we are early, intermediate or late adaptors.
What is **key** is the way we appraise evidence into context. Ideally we need to consider:

- Systematic reviews that pull research studies together that allow a scientific ‘weighing up’ of what works
- Studies that help elucidate real-world practice eg international pharmacovigilance audits, that tell us how a treatment works outside a controlled trial
- Qualitative research, ideally in the form of a systematic review - brings together the voices of patients and caregivers, and the health care professionals who care for them, giving a unique insight into experiences and views about interventions
Palliative care needs an ecosystem that supports *only the very best science*, using the *most appropriate methods* that *apply to patients with messages that are truly accessible to clinicians*.

This ecosystem extends to us.

*We must be discerning readers of that science*, even when studies are published in high-quality journals.

If patients are to have life-changing care we must assimilate only the best evidence, combine it with our individual clinical expertise, and know when and who to go to for that specialist source of wisdom when we lack it.
Call for papers closed 16 May!

THANK YOU FOT ALL WHO SUBMITTED
Understanding and Applying Research Methods in Practice

The APM & PCRS Research Course

https://apmeducationhub.org/events/apm-pcrs/
The APM and PCRS Research Course

Understanding and Applying Research Methods in Practice

June 2022

Introduction

A joint APM and PCRS course on Understanding and Applying Research Methods in Practice, has been developed by the APM Research & Ethics Committee and the PCRS Executive Committee. The course will be facilitated by national leaders in Palliative and End of Life Care Research, and be held over 3 weeks, with pre-work being issued in Week 1, a virtual day held in Week 2 and an in-person day to finish the course. The course has been designed to support all clinicians seeking to begin their journey in palliative care research, with the programme constructed to address the research competencies for Palliative Medicine Trainees. Places on the course are limited.

Programme Overview

<table>
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<th>Week</th>
<th>Topic</th>
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<tr>
<td>Week 1</td>
<td>Pre-work is issued</td>
<td>Wednesday 8 June</td>
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<tr>
<td>Week 2</td>
<td>Research Methodology and Appraising the Literature</td>
<td>Wednesday 15 June</td>
<td>Virtual, MS Teams</td>
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<td>Week 3</td>
<td>Research – Getting Started</td>
<td>Wednesday 22 June</td>
<td>In-person, Leeds</td>
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Fees – Full Course

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<td>Non-Member Early Bird</td>
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Fees – Virtual Day Only (15 June)

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<td>90</td>
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Resources

Juniors

Go to Junior Resources Page

Postgraduate Medical Education

Go to PME SIF Resources Page

2022 Recordings

https://apmeducationhub.org/postgraduate-medical-education-sif/
The Special Rules process: financial support for people who are nearing the end of life

Hospice UK Clinical ECHO

Dr Emily Pikett
Clinical Policy Advisor and Clinical Lead for the Special Rules reform Department for Work and Pensions

June 2022
Background to the Special Rules

• The Special Rules allow people who are nearing the end of their life to apply for benefits via a fast-tracked and simplified process

• The process is in place for claims to ESA, UC, PIP, DLA and AA with:
  • no requirement for a medical assessment
  • no waiting period
  • most cases get highest level of award

• Since the early 1990s, the Special Rules have applied to those with a predicted life expectancy of less than 6 months to live
Improvements from 4th April 2022

• New regulations live from 4th April 2022 impacts two working age benefits:
  • ESA
  • UC

• Special Rules criteria changed to allow applications via the fast-tracked process for individuals who may have less than 12 months to live

• Social Security (Special Rules for End of Life) Bill [HL] was introduced on 11th May 2022 to extend this change across remaining 3 benefits:
  • PIP
  • DLA
  • AA
Intentions of policy change

- Align definition used in the welfare system with definition of ‘end of life’ that is used across the NHS:
  - that ‘a person is approaching the end of life when they are likely to die within the next 12 months’

- Improve access to financial support for those nearing the end of life

- Raise awareness of financial support available for those nearing the end of life

- Include conversations about financial support as part of holistic approach to supporting patients with advanced progressive illnesses, poor prognoses or terminal conditions
Special Rules Guide

• Written for clinicians following extensive engagement and supported by visual flowchart

• Single source of information about improvements to the criteria and how to provide the relevant medical evidence
  • role of DS1500
  • role of new form, SR1

• *NEW* clinical indicators section

• www.gov.uk/dwp/special-rules

• DWP financial support for patients who are nearing the end of life: (publishing.service.gov.uk)
DWP financial support for patients who are nearing the end of life:

A flow chart for clinicians to explain when to use the DS1500 or SR1 form following improvements to the special rules process.

1. Patient is identified as nearing the end of their life.
2. Does your patient have an estimated prognosis of less than 6 months to live?
   - Yes: Complete a DS1500 form which can be accepted for all benefits.
   - No: Does your patient have an estimated prognosis of less than 12 months to live?
     - Yes: Is your patient aged 18 to State Pension age and considering or claiming UC* or ESA?
       - Yes: Complete a SR1 form.
       - No: 
     - No: Please complete a DS1500 form when you consider your patient has an estimated prognosis of less than 6 months to live. This can be used for all benefits.

*There are some exceptions if your patient is 16 or 17 years old.

For more information, please go to www.gov.uk/dwp/special-rules
DS1500 form

• If clinician thinks a patient has an **estimated prognosis of less than 6 months to live**

• Accepted across all benefits – PIP, DLA, AA, UC and ESA

• Can be returned via
  • NHS spine portal
  • email: pip.e-ds1500@dwp.gov.uk
  • post

• Information about obtaining electronic / hard copies of DS1500 and where to return these forms can be found at [www.gov.uk/dwp/special-rules](http://www.gov.uk/dwp/special-rules)
SR1 form

• If clinician thinks a patient has **estimated prognosis of 6 – 12 months to live**

• Accepted for UC and ESA – the 2 benefits that have currently been impacted by the change

• Can be returned via
  • email: [form.e-SR1@dwp.gov.uk](mailto:form.e-SR1@dwp.gov.uk) **PREFERRED**
  • post

• Information about obtaining electronic / hard copies of SR1 and where to return these forms can be found at [www.gov.uk/dwp/special-rules](http://www.gov.uk/dwp/special-rules)
Summary

• Individuals who are thought to be in their final year of life are now able to access fast-tracked financial support via ESA and UC

• Bill is in parliament to extend this criteria across PIP, DLA and AA

• Resource can be found on gov.uk to assist clinicians and others in navigating the Special Rules process during this transition period

• This presentation is part of wider work to raise awareness of the financial support available for those nearing the end of their lives across the palliative care community
Questions?
Developing the palliative care workforce:

A proposal for Palliative & End of Life Care Career Pathway and Education Development programme

Developing a palliative and end of life care career pathway and education development programme for nursing and allied health professionals
Aims of the programme:

The programme aims are to:
• Develop and promote a career pathway and education framework for those nursing and allied health professionals aspiring to work at all levels in specialist palliative and end of life care;
• Improve future supply of aspirant specialist workforce with appropriate education and development opportunities;
• Ensure the future and existing workforce providing general and specialist palliative and end of life care can access education and development opportunities with the underpinning knowledge and competencies they need for their role
1. Aspirant PEOLC Professional Student Programme
   Target audience: Pre-registration nursing associate, nursing & AHP students

2. Early career PEOLC Professional Development Programme
   Target audience: Registered level practitioners new to PEOLC services/roles & those aspiring to enhanced and advanced roles

3. PEOLC Care Professional Development & Clinical Leadership Programme
   Target audience: Registered level practitioners appointed to Enhanced and Advanced roles

4. PEOLC Consultant & Strategic Leader Development Programme
   Target audience: Strategic Leads, Consultant level practitioners

Clinical practice

Specialist education

Leadership & management

Research, EBP & QI
Learning & development includes:
workplace-based learning, coaching/supervision, action-learning sets, CPD, accredited modules/courses
Aligned to nationally defined curricula/outcomes/capabilities*

*Eg: End of Life Care Learning Outcomes
HEE Multi-professional Framework for Advanced Clinical Practice & PEOLC credential
Career Pathway and Education Framework for Nursing & AHPs in PEOLC

4 pillars of professional practice

- Consultant level
- Advanced level
- Enhanced level
- Registration level

Aspirant PEOLC Professional Student Programme

Early Career PEOLC Professional Development Programme

PEOLC Professional Development & Clinical Leadership Programme

PEOLC Consultant level & Strategic Leader Development Programme

Learning & development includes:
- workplace-based learning
- coaching/supervision
- action learning sets
- CPD
- accredited modules/courses

Aligned to nationally defined curricula/outcomes/capabilities

Specialist Palliative & EOL Care Workforce

General & Specialist PEOLC Workforce

4 pillars of professional practice
Career Pathway: Levels of practice

Figure 5 There is a probable gradient of specialist knowledge across levels of practice.
Pre-registration

Registration level

Enhanced level

Advanced level

Consultant level

Advanced level practitioner (ALP) - PEOLC

Advanced Clinical Practitioner (ACP) - PEOLC

Generalist & Specialist PEOLC

Specialist PEOLC
Pre-registration
Registration level
Enhanced level
Advanced level
Consultant level

Supportive
Assistive FdD
Pre-registration
Registration Novice & Intermediate BSc/PGC
Enhanced PGC/PgD
Advanced Masters
Consultant PhD/Doctorate

Fundamentals of PEOLC
30 credits equivalent
Fundamentals of PEOLC + Enhanced PEOLC (30) + Advanced psycho level 2/adv comms
Total equivalent to 120 credits (PgD)

Fundamentals of PEOLC practice + Enhancing PEOLC (30) + Advanced psychol level 2/adv comms + Advancing PEOLC practice and services (180)

Advanced practitioner (ALP) - PEOLC

Advanced level

HEE Advanced Clinical Practitioner (ACP) - PEOLC

Specialist PEOLC

Generalist & Specialist PEOLC
<table>
<thead>
<tr>
<th>Registration level</th>
<th>Enhanced level</th>
<th>Enhanced/Advanced level</th>
<th>Advanced level (Alternative to HEE ACP – PEOLC)</th>
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<tbody>
<tr>
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<td>Registered Nurses with experience in specialist PEOLC</td>
<td>Registered Nurses with experience in specialist PEOLC</td>
<td>Registered Nurses with experience in specialist PEOLC</td>
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<tr>
<td>All</td>
<td>Specialist PEOLC Experienced in PEOLC &amp; those aspiring to advanced level roles</td>
<td>Specialist PEOLC Experienced in PEOLC &amp; those aspiring to advanced level roles</td>
<td>Specialist PEOLC Experienced in PEOLC &amp; those aspiring to or in advanced level role (NOT HEE ACP-PEOLC)</td>
</tr>
</tbody>
</table>
10 Things FAB TEAMS Do!

1. Create a shared vision of the future, and move towards it together.

2. Challenge the status quo together, so no one has to face scary change alone.

3. Sign up to... (Change is built on a commitment to a different future, not performance management)

4. Value and embrace difference and healthy conflict.

5. Help everyone in the team to feel safe and innovate.

6. Communicate → TALK! (Don’t rely on email)

7. Are KIND to each other: Get to know each other as people - care about the little things (like tea and cake!)

8. Think the best of each other - so when something goes wrong you don’t blame other people’s incompetence.

9. Achieve Win-Win for all team members

10. Are highly productive - the sum is greater than its parts.

@HorizonsNHS
What my grandmother knew about dying

As a physician, I trained in the delicate art of preparing people for death. Losing Harriet made me see the work differently.

By Rachael Bedard
March 6, 2022

What my grandmother knew about dying
THANK YOU
Evidence Update Max Watson
APM Update Matt Dore
Special Rules benefits for people with a terminal illness Dr. Emily Pikett DWP
Nurse and AHP Palliative Career development Vanessa Taylor University of Central Lancashire
The role of Hospice services across the UK HUK and Nuffield Trust Dominic Carter HUK

Chat Box
• Your Questions
• Resources
• Information /innovations
• Email clinical@hospiceuk.org

Please share resources, powerpoint, links etc. with those who would benefit.
Next session: 14 September 2022

15:30 – 17:00
May this be the day
We come together.
Mourning, we come to mend,
Withered, we come to weather,
Torn, we come to tend,
Battered, we come to better.
Tethered by this year of yearning,
We are learning
That though we weren't ready for this,
We have been readied by it.
We steadily vow that no matter
How we are weighed down,
We must always pave a way forward.
This hope is our door, our portal.
Even if we never get back to normal,
Someday we can venture beyond it,
To leave the known and take the first steps.

So let us not return to what was normal,
But reach toward what is next.
What was cursed, we will cure.
What was plagued, we will prove pure.
Where we tend to argue, we will try to agree,
Those fortunes we forswore, now the future we foresee,
Where we weren't aware, we're now awake;
Those moments we missed
Are now these moments we make,
The moments we meet,
And our hearts, once altogether beaten,
Now all together beat.

Amanda Gorman
1/1/2022
HAPPY HOLIDAYS!