

Supporting Scottish Grief & Bereavement Care Workstream Annual Report 2019–2020



PARTA ABOUT US

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OUR VISION

To support the delivery of safe, effective and person-centred care which is provided, before, at and after death, to those who are at the end of life and to the bereaved, within a culture of support for staff health, wellbeing and resilience.

WHAT DO WE DO?

- + Deliver bereavement-related educational interventions and support to health and social care staff in Scotland
- + We aim to enhance professionals' preparedness to manage care and communication around the time of death and in bereavement
- + We have historically had a particular focus on the needs of medical staff but are increasingly broadening out this remit to consider all those who work within health and / or social care

WHY DO WE DO IT?

Our work is founded upon acceptance that events leading up to and surrounding death, and patients and families experience of these, will significantly influence the nature of bereavement. Therefore, optimal handling of the preparation for, and support around all deaths (including those that are expected and unexpected) by health and social care professionals is an important part of improving bereavement care in Scotland.

This report provides a summary of some of our key achievements of 2019–20, and the impact of these on the national landscape of bereavement-related education and care in Scotland, and in some instances beyond.







PART B 2019–20 ACHIEVEMENTS

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1. BEREAVEMENT EDUCATION CONFERENCE 2019

A particular focus this year was the planning and hosting of NES' inaugural Bereavement Education Conference, **Starting with the end in mind; A realistic approach to bereavement and resilience** which took place on 11 November 2019 at the Royal College of Surgeons of Edinburgh. #NESBereavement2019

Aims

- To improve knowledge and understanding of the impact of communication around the time of death on those who are bereaved thereby reducing unnecessary harm
- + To provide an opportunity for networking with peers and raise awareness of new educational resources within undergraduate / postgraduate teaching and learning
- + To provide guidance on the benefits of individual and / or group reflective practice to enhance coping mechanisms when dealing with bereavement-related situations in order to stay well at work

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Programme



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http://www.sad.scot.nhs.uk/media/16274/ nes-bereavement-conference-2019-finalisedprogramme.pdf

The Chief Medical Officer for Scotland, Dr Catherine Calderwood <u>opened the event (https://vimeo.</u> <u>com/391455065)</u> and included reference to it in her 11 December 2019 article in *The Scotsman* newspaper, *'There's no better Christmas present for those who've lost a loved one than this'.*



 Grief, loss and bereavement is something that we all share and to hear Catherine's personal / professional experience of this really set the tone for the day.



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She was followed by Dr Donald Macaskill (CEO, Scottish Care) whose presentation <u>Beyond the</u> <u>Full Stop: Bereavement and the Power of Human Story</u> (<u>https://vimeo.com/392425434</u>), included reference to work ongoing to develop a <u>Bereavement Charter for</u> <u>Scotland (http://www.sad.scot.nhs.uk/bereavementcharter</u>), which NES is currently involved with.



+ Thought-provoking.

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- + Incredible presentation. Such an eloquent and engaging presenter which set the tone perfectly for the conference.
- + Great reminder of the importance of medical humanities and the art of medicine.
- + A really poignant reminder that sometimes all people really need from us is to listen!

A strong emphasis was placed on case scenarios throughout the day, to maximise the potential for practical clinical application, with delegates having the opportunity to explore a wide variety of challenging bereavement-related topics across plenary and workshop sessions. There were many rich and wide-ranging discussions with fantastic sharing of ideas and knowledge. The morning focussed on the delivery of care and optimising good communication, with the afternoon sessions exploring themes surrounding staff wellbeing.

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MORNING PROGRAMME

- Dealing with Sudden and Unexpected Deaths:
 Perspectives from the Scottish Ambulance Service
- + Bereavement Following Substance Use
- + Spiritual Considerations Around End of Life
- + Anticipatory Grief in Dementia Before the Time of Death
- Helping Children who are Bereaved: The Impact of Language and Practice
- + Understanding the Needs of LGBT People in Relation to Death, Dying and Bereavement
- Managing Legal Processes Following a Death

 including Medical Certification of Cause of
 Death and Interaction with the Procurator Fiscal
- + Supporting those with Profound and Multiple Learning Disabilities and their Unpaid Carers around Bereavement and Loss

AFTERNOON PROGRAMME

- Psychological Resilience and Coping with Bereavement at Work
- The Three R's; Realism, Reflection and Resilience
- Staying Well at Work
- Should Staff Attend Patient Funerals?
- Managing Bereavement in the Workplace
 what is helpful and what is not?

Our closing speaker was **Adam Kay**, author of the award-winning bestseller, *This is Going to Hurt*.

We were grateful to a wide range of individuals and organisations for their involvement in delivering a highly engaging and thought-provoking conference programme. Some of these are included below.





CONFERENCE ATTENDEES

Due to an overwhelming demand for places we were forced to close the registration process early, at that stage having received over 750 expressions of interest. Particular attention was paid to ensuring that conference places were allocated to as broad a range of health and social care professionals as possible.





CONFERENCE EVALUATION AND FEEDBACK

NES received extremely positive feedback from the 150 professionals who attended. Delegates welcomed the opportunity for attention to be given to rarely-covered topics and remarked positively on the conference's atmosphere of compassion and kindness.

Approximately 90% of delegates stated that the aims of the conference were met and all respondents either indicated that their personal objectives for attending were met in full (80%) or partially (20%). Evaluation forms were completed by approximately 65% of attendees.

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- + I had the chance to learn from passionate people at the top of their game and at the cutting edge of the Bereavement revolution.
- + One of the best run conferences I have ever been to.
- + Powerful in all cases to hear real life stories from various perspectives.
- + All excellent presentations highlighting death on different areas of healthcare and the impact this can have on everyone involved.
- A strong reminder of how our colleagues can
 [be] affected by very sad situations at work.
 They may not talk about them, but it would be worth asking if they are OK.



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90% of delegates stated that the aims of the conference were met.

100% of delegates stated that their personal objectives for attending were met: **80%** in full and **20%** partially.

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CONFERENCE FILM CLIPS

Openly accessible, short film clips from workshop and plenary speakers are available to view on our Support around Death website: www.sad.scot.nhs.uk. These provide a brief overview of the key take-home learning points from each session and will be of relevance to both those who were at the conference as well as health and social care professionals who were not.





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2. DEVELOPMENT OF A BEREAVEMENT CHARTER FOR SCOTLAND

This year we have contributed to the development of a human rights-based <u>Bereavement Charter for Scotland</u> (<u>http://www.sad.scot.nhs.uk/bereavement-charter</u>) as part of a national coalition of individuals and other organisations who are overseeing this work.

The Charter, which is based on human rights principles, has brought together a set of core statements which are really about a description of what Scotland could be like in order that we better support an adult, child or group of people who is / are experiencing bereavement. The Charter will be accompanied by a guidance document that will provide additional contextual detail and, as the core statements are intended to be generic for use by everyone, this will include consideration of some specific contexts of grief and death:

- + Children and young people
- + Trauma, including murder and suicide
- Anticipated death and disenfranchised grief
 dementias, frailty, neurological conditions
- + Maternal, neonatal and perinatal deaths

We have been involved in supporting a consultation process, with face to face stakeholder engagement events, which will be followed by an online survey, which together will lead to further refinement of the draft Charter and guidance, ahead of their anticipated launch later in 2020.



https://vimeo.com/395685686







3. TOOLKIT OF EDUCATIONAL RESOURCES

With input from a wide range of subject and clinical experts throughout this year we have continued to enhance our range of bereavement-related training materials for health and social care professionals – by developing new materials and updating others.

The majority of these are all openly accessible on our Support around Death website: <u>www.sad.scot.nhs.uk</u>.

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MEDICAL CERTIFICATION OF CAUSE OF DEATH

We have had another very productive year of working closely with the Death Certification Review Service (DCRS) to continue to produce educational resources to support certifying and non-certifying staff.

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NES have been totally brilliant in helping us promote guidance on what can be a difficult subject to discuss, even for healthcare professionals. The e-learning modules are outstanding and the film clips have been ideal in summarising the issues in a readily understandable form.

Dr C George M Fernie

Senior Medical Reviewer, Healthcare Improvement Scotland, Death Certification Review Service + SHORT FILM

A short film, <u>Death Certification, the Review Process</u> and <u>Discussions with Families (https://vimeo.</u> <u>com/395688758)</u>, featuring Dr George Fernie (Senior Medical Reviewer, DCRS) talking to Dr Katherine Ritchie (Scottish Clinical Leadership Fellow and Emergency Medicine Registrar). This film emphasises the importance of discussing the content of the Medical Certificate of Cause of Death (MCCD) with people who are bereaved to reduce any unnecessary harm that might result from sub-optimal communication.









+ JOINT WORKSHOP

A joint workshop at the inaugural NES Bereavement Conference in November 2019 featuring Dr George Fernie (DCRS) and David Green Head of Scottish Fatalities Investigation Unit, Crown Office and Procurator Fiscal Service (COPFS) that emphasised the close working relationship between the DCRS and COPFS to enhance the quality of service. Film clips from each speaker, summarising this workshop are available.

https://vimeo.com/392434038 https://vimeo.com/393646800

+ FREQUENTLY ASKED QUESTIONS

A frequently asked questions document for non-certifying staff who may interface with people who are bereaved around the time of receipt of the MCCD. This has been developed in partnership with NHS Board Bereavement Strategic Leads and Coordinators and the DCRS and will be available on the NES Support around Death website: <u>www.sad.scot.nhs.uk</u> from Spring 2020.



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+ E-LEARNING MODULES

The numbers of doctors completing the two e-learning modules (previously launched by Healthcare Improvement Scotland / NES) has continued to rise across all Health Boards this year. The modules are designed to support certifying doctors to complete Medical Certificates of Cause of Death (MCCDs).





Death Certification: Identifying Common MIstakes **1070**

individuals completed (406 this financial year)



MODULE 2

Certification of Deaths in the Community

278 individuals completed

(68 this financial year)



Find the modules here:

https://learn.nes.nhs.scot/6462/death-dying-and-bereavement/death-certification





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ANIMATED FILMS

We have continued to see usage figures rise across our suite of animations (http://www.sad.scot.nhs.uk/videowall), which support practitioners in conversations around death, dying and bereavement. The short length and scenario-based focus of these films enhances learning and relevance within already busy clinical and educational environments. Delivering the news of a death by telephone (https://vimeo.com/328655124) was the most recent film to launch, in Spring 2019.

Each animation is accompanied by a downloadable leaflet of key learning points and in some cases, a guide as to how the film can be used in a group teaching scenario. Over 115 professionals have acted as script reviewers in the process of producing our bereavement-related animations to date.

Fantastic videos. Use them regularly for teaching.

+ Great training resource that would be helpful to many different health and social care professionals.





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The films overall have now been viewed over 37,000 times, a number which steadily rises on a monthly basis, and a 40% increase on the overall total views since 1st April 2019.

We also continue to receive positive feedback regarding these materials and requests for permission to use them on a national and international basis within teaching courses and programmes.

We have also added closed caption subtitles to all but one of our animations this year, helping to improve accessibility.



The films have been used in teaching programmes in Australia, Ireland, India and all countries within the UK



40% increase on overall total views since 1st April 2019



Collectively, the suite of animations as a whole have been viewed over

37,000 times

These can be accessed openly at: www.sad.scot.nhs.uk/video-wall

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BEREAVEMENT FOLLOWING SUICIDE

We have identified a gap in the availability of educational resources for healthcare professionals on:

- + how to support someone who is bereaved following suicide
- + the procedural / practical actions required after a death by suicide or suspected suicide
- + how to look after oneself / your team when a person who you have been caring for dies by suicide

In response, we have begun work to scope out how NES may be able to help fill these gaps. It is hoped that in collaboration with subject and clinical experts, new resources on these topic(s) will launch later in 2020.

SUPPORTING LGBT PEOPLE AROUND DEATH AND BEREAVEMENT

Following our work with a number of third sector organisations last year (including Stonewall Scotland, the Scottish Trans Alliance and LGBT Health and Wellbeing) on the development of educational resources for healthcare professionals on <u>Supporting LGBT+ people around</u> <u>death and bereavement (http://www.sad.scot.nhs.uk/ media/16262/lgbt-bereavement-leaflet-updated-feb-</u> <u>2020-final.pdf</u>), this year we have responded to feedback on our leaflet resource by making some minor text updates. The leaflet and supporting information remain available on our website <u>http://www.sad.scot.nhs.uk/bereavement/</u> <u>supporting-lgbtplus-people-around-bereavement.</u> Dissemination has been broad including specific targeting of equality and diversity networks.



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CONFIRMATION OF DEATH

We have worked this year with the team within NES who has been overseeing the development of resources to support registered healthcare professionals with confirmation of death. This has included development of the Support around Death website (http://www.sad.scot. nhs.uk) to host the new materials produced, to help ensure that these educational resources are as widely publicised as possible to support practitioners across Scotland.

ORGAN AND TISSUE DONATION

We have begun work with colleagues from the Scottish National Blood Transfusion Service and NHS Blood and Transplant on the production of films which will help inform healthcare professionals about organ and tissue donation and how to explore these topics with families.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

This year we have added closed caption subtitles to the film <u>Do Not Attempt Cardiopulmonary Resuscitation –</u> <u>NHS Scotland Policy and Clinical Practice (https://vimeo.</u> <u>com/364270471</u>) to enhance its accessibility and featured a new link to this resource in a more prominent position on the Support around Death website <u>http://www.sad.</u> <u>scot.nhs.uk</u>. Work has also begun to embed pre-existing DNACPR training materials within the website to make it easier for practitioners to identify and utilise these as part of their learning and development.



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4. SUPPORTING NHS HEALTH BOARDS

In addition to the production of bereavement themed educational resources for health and social care professionals, we have continued to support NHS Health Boards with regards to bereavement care in a number of other ways.



NHS BOARD BEREAVEMENT STRATEGIC LEADS AND COORDINATORS NETWORK

We have provided ongoing support to this network across Scotland this year, including through the hosting of quarterly learning events which garnered good attendance and engagement, and provided an opportunity on a national basis to:

- share learning, best practice information or policy updates – information which can then be disseminated within geographic Health Boards, e.g. the sharing of information on appropriate patient belonging bags for use following a death when handing personal belongings back to families
- + highlight newly created educational resources, support services or events of relevance
- + raise questions regarding bereavement-related care or practice and seek support on possible solutions

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We welcomed over 15 speakers to four one-day network meetings in 2019–20, representing a wide range of organisations including, e.g. tide (Together in Dementia Everyday), Carnegie UK Trust, NHS Greater Glasgow & Clyde Psychological Trauma Service, Voluntary Health Scotland and Cruse Bereavement Care Scotland; each delivering informative sessions and facilitating thought-provoking discussions. Topics explored included:

- + Carer perspectives on dementia, anticipatory grief, bereavement and support
- + Combating loneliness and building stronger communities
- + Bereavement experiences of Gypsies and Travellers
- + Mass casualty events and traumatic bereavement
- + Loneliness and social isolation in Scotland
- + Confirmation of death

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+ Digital inheritance, digital assets and planning for a digital legacy

We have received positive feedback from network members on the benefits that they gain from involvement with the group.

Through the Bereavement Strategic Lead and Coordinators Network NES has created a space which allows innovations and good practice within bereavement care to be shared amongst Boards; It has allowed Boards to learn from the experiences of colleagues, both the opportunities and the challenges and to consider how projects and innovations can be adapted to particular contexts. Whilst there is opportunity to share practice, and availability of excellent training opportunities – it is perhaps the peer support which I value most; the sense that you are not alone and are part of something bigger in prompting and developing Bereavement Care as a core part of people centred care.

Mark Evans, Spiritual Care & Bereavement Lead, NHS Fife

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This year we have drafted a new information guide for network members, to help familiarise them with the support that NES can provide for their bereavement role and the work of the group. We also continue to manage an online community of practice for the group.

Following the success of a new initiative in 2018–19 to offer support to network members to attend educational and development events, relevant to their bereavement role, we have continued with the availability of this funding throughout this year. Other Board Bereavement Leads have then benefitted from hearing about key learning points and take-home messages when information has been disseminated through presentations delivered at quarterly network meetings.

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SHORT TERM DEVELOPMENT FUNDING AWARD FOR NHS HEALTH BOARDS

We identified an opportunity to further support NHS Boards to create and enhance bereavement-related developments at local level last year and following the success of a newly implemented award scheme, we have re-run this in 2019–20.

As a result, we provided three Health Boards with small grant funding to undertake a variety of projects, including:

- + Development of a group of 'Bereavement Champions' to provide expertise on appropriate procedure and consideration around death, dying and bereavement
- Review of Last Offices Standard Operation Procedure to reflect person-centred care, followed by production of an education package for staff
- Pilot simulation-based training on the final care of dying patients and preparation of the deceased

Following evaluation, the learning from each initiative will be shared with all Health Boards across Scotland, in the hope that some pieces of work may be able to be replicated elsewhere.

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USE OF NES' SUPPORTING SCOTTISH GRIEF AND BEREAVEMENT CARE THISTLE IMAGE

We have seen an increase in the use of our branding across NHS Boards this year. The thistle image (originally commissioned by NES for the national NHS Scotland *'When Someone has Died'* booklet <u>https://www.nhsinform.</u> <u>scot/media/1503/when-someone-has-died-2016.pdf</u>) is being utilised more widely on bereavement-related written materials and signage in a variety of different ways around Scotland; each as part of initiatives to support improvements to bereavement care. Examples of uses approved this year include:

- + Door and desk signs in ICU / HDU hospital settings
- + Identification of bereavement-related documentation
- + Door signs for operating theatres during last offices
- + Motif for concealment trolley used to transfer deceased patients

One other notable example is the adaptation of the image as a motif on the Bereavement Charter for Scotland that is in development.









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5. STAFF HEALTH AND WELLBEING

Throughout this year, and informed by themes discussed at our 2019 conference, we have continued to consider how caring for those who are at end of life and those who are bereaved can impact upon staff themselves.

In response, we are developing a video based in a Scottish Emergency Department, which will capture the experiences of a multidisciplinary team (both clinical and non-clinical members) on dealing with death and bereavement in the course of their work, often on a daily basis. It will explore themes of staff health and wellbeing and will share simple, practical ways in which staff can support themselves and each other.

This development was originally inspired by films which focus on similar themes of dealing with issues of resilience for emergency personnel who encounter death in their professional roles, within an <u>Air Ambulance</u> (https://www.youtube.com/watch?v=DY60ZOWBvDc) and <u>Mountain Rescue (https://www.youtube.com/</u> watch?v=qabCvFwmNyo) team, produced by a junior doctor in England.

We look forward to the film's launch in the summer of 2020.

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6. DIGITAL

SUPPORT AROUND DEATH (SAD) WEBSITE

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This year, whilst continuing to oversee the day to day management of the website, we have overseen the development of new content and updates to the Support Around Death website that provides a range of information for health and social care professionals related to care before, around the time of and after a death.

The SAD website is openly accessible, has relevant up-todate content and utilises a layout that is easy to navigate. This enables users to:

- + Access information and educational resources on bereavement and care around the time of death
- + Discuss and network with professional colleagues in a secure community of practice forum

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+ Learn and share best practice guidelines and research

Usage data this year demonstrates that the SAD website is an increasingly well-used resource for health and social care staff across Scotland and abroad:





Over **3%** increase in website users versus those seen in the previous financial year 2018–19



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The website has been accessed from **119** countries and users view on average **2** pages per visit

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Top 10 most popular pages (total views this year)



6%

5%

4%

Homepage <u>http://www.sad.scot.nhs.uk</u>

Video wall http://www.sad.scot.nhs.uk/video-wall

Pregnancy, stillbirth and neonatal loss http://www.sad.scot.nhs.uk/bereavement/ pregnancy-loss-stillbirth-and-neonataldeath

Bereavement main page http://www.sad.scot.nhs.uk/bereavement

How and when to report a death to the PF http://www.sad.scot.nhs.uk/atafter-death/ involvement-of-the-procurator-fiscal/ how-and-when-to-report-a-death-to-theprocurator-fiscal/ 3%

3%

3%

3%

3%

Sudden or Unexplained Death http://www.sad.scot.nhs.uk/bereavement/ suddenunexplained-death

Children who are bereaved http://www.sad.scot.nhs.uk/bereavement/ children-who-are-bereaved

Communication around the end of life with the bereaved <u>http://www.sad.scot.nhs.uk/bereavement/</u> <u>communication-around-the-end-of-life-with-</u> <u>the-bereaved</u>

Death certification http://www.sad.scot.nhs.uk/atafter-death/ death-certification

At / after death main page http://www.sad.scot.nhs.uk/atafter-death







A notable development this year on the SAD website is the creation of a <u>NES Bereavement Conferences</u> (http://www.sad.scot.nhs.uk/nes-bereavementconferences) section. This has allowed us to upload information, including speaker film clips from the inaugural 2019 Bereavement Conference (http://www.sad.scot.nhs. uk/nes-bereavement-conferences/2019-conference) and will also act as a repository for details on the upcoming event on Friday 20th November 2020 including the registration process and the programme and film clips following the conference.



TURAS LEARN

We have continued to maintain and add to our page on Turas Learn, NES' platform for learning and support resources this year, providing information related to death, dying and bereavement (https://learn.nes.nhs. scot/1666/death-dying-and-bereavement), e.g. on death certification, supporting LGBT people around death and bereavement, our educational animated film resources and the Support Around Death website: http://www. sad.scot.nhs.uk. We will further expand this content throughout the upcoming year.

We also have maintained our presence on the Scotland Deanery website: <u>https://www.scotlanddeanery.nhs.scot/</u> <u>your-development/death-dying-and-bereavement</u>.







7. COMMUNICATIONS

INVOLVEMENT WITH RELATED WORK

We continue to represent NES on nationally aligned pieces of work, having team representation on e.g. the Death Certification Review Service Management Board, Palliative & End of Life Care National Implementation and Advisory Group, the Death Certification Implementation Leads Group and the Scottish Government Stillbirth Bereavement Sub Group.

SOCIAL MEDIA

Through our <u>@NES_Bereavement</u> Twitter account and the corporate NES social media accounts we have regularly shared information about our work and educational resource creation.

Approaching **1,200 followers**

CONFERENCES & EVENTS

This year we welcomed the opportunity to attend several national conferences and events (as an exhibitor or poster presenter) to share information about NES' bereavement work, including:

- + Scottish Medical Education Conference, May 2019, Edinburgh
- + NHSScotland Event, May 2019, Glasgow
- Royal College of Paediatrics & Child Health Conference, May 2019, Birmingham
- Royal College of Obstetricians and Gynaecologists
 World Congress, June 2019, London
- + Scottish Partnership for Palliative Care Annual Conference, September 2019, Edinburgh
- + Association for Palliative Medicine Palliative Care Congress, March 2020, Telford







E-NEWSLETTER

We have spent time this year refreshing the look and feel of our quarterly e-Newsletter with new seasonal banner designs: <u>http://www.sad.scot.nhs.uk/e-newsletter</u>

In 2019–20, subscriber numbers have risen to approaching

1,200 people

and we have seen



in total across our

4 publications

The e-Newsletter has enabled us to share information on bereavement-related education and training, events and publications.





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PART C: LOOKING AHEAD TO 2020–21



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We plan to continue to strive to influence the national strategic agenda on death, dying and bereavement education for health and social care professionals by:

- + Launching a bereavement national training framework for medical staff to support doctors in conversations with patients and families around the time of death and in bereavement, with a view to enhancing existing medical curricula
- + Continuing to develop educational resources to build a toolkit of materials to support the implementation of this framework, including a mobile app to support bereavement related communications, a film to focus on the needs of staff who are exposed to situations of death and bereavement at work and resource(s) on supporting those bereaved following suicide
- Hosting another annual conference to support the delivery of high-quality bereavement-related educational initiatives and encourage networking, shared learning and ultimately increase the profile of bereavement care in Scotland

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- + Continuing to work with multi-sector partners (including third sector, NHS and social care) on the development of a human-rights based Bereavement Charter for Scotland
- Developing the evidence base to demonstrate the need for improvements to bereavement education e.g. though building on the findings of our literature reviews and previous surveys of junior doctors and education providers
- Facilitating national learning networks for sharing of best practice in bereavement care
- Producing quarterly e-newsletters, managing online communities of practice and an active social media account
- Continuing to expand and develop the Support Around Death website, to provide an openly accessible, educational platform for health and social care professionals to access bereavement-related training materials and information

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This resource may be made available, in full or summary form, in alternative formats and community languages. Please contact us on **0131 656 3200** or email **altformats@nes.scot.nhs.uk**.



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