



**Irish Neonatal Health Alliance (INHA) and Peas in a Pod: Loss in a multiple pregnancy**

**Oireachtas Briefing Paper: Baby Loss**

## Contents

About the Irish Neonatal Health Alliance (INHA).....	2
Facts and Figures.....	2
The Cost of Baby Loss.....	3
The State Records .....	6
Entitlement to Paid Leave when your Baby Dies .....	9
Changes to Maternity Leave and Paternity Leave .....	10
Prevention of baby loss in a multiple pregnancy.....	11
Emotional Supports to Bereaved Parents in the Community.....	15
Covid 19 and Baby Loss.....	17

## About the Irish Neonatal Health Alliance (INHA)

The Irish Neonatal Health Alliance ([www.inha.ie](http://www.inha.ie)) is a registered charity (CHY 21984, RCN-20100100). Our mission is to partner with, educate and empower families, healthcare professionals, educators, political decision makers and industry stakeholders on issues relating to the neonatal field.

Peas in a Pod: Loss in a Multiple Pregnancy works in partnership with the Irish Neonatal Health Alliance. It was set up by a group of bereaved parents who lost a baby (babies) in a multiple pregnancy. It acts as an awareness and advocacy group.

This document outlines our concerns in relation to baby loss and our asks of the Government.

## Facts and Figures

Baby loss is not uncommon. The latest figures available from the National Perinatal Epidemiology Centre are from 2017 and they show that in Ireland 381 babies died. Stillbirths accounted for 235 (61.7%), early neonatal death accounted for 111 (29.1%) and late neonatal deaths accounted for 35 (9.2%). Baby deaths from multiple births accounted for 12.4% of all baby deaths (Source:

<https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinataIMortalityinIrelandAnnualReport2017.pdf>).

## The Cost of Baby Loss

The death of a baby is something that parents are often completely emotionally and financially unprepared for. Many bereaved parents must rely on the generosity of friends and family or must take out a bank loan to pay for their baby's burial or cremation and funeral. In the darkest moment of a bereaved parent's life, they should not have to endure the financial burden of meeting funeral costs.

### The Costs Involved

These costs can involve buying a new grave, burial in a family plot or burial in the angel's plot. Some maternity hospitals provide bereaved parents with a coffin for a baby to be taken home in and buried, others do not when the parents are holding a private burial from their own home or funeral home.

If parents choose to cremate their baby's body, they can choose between the six crematoria on the island of Ireland. Three of the crematoria charge no fee to cremate a baby and three charge between 160 euro and 330 euro (Source: [www.aftering.com/crematoria-in-ireland/](http://www.aftering.com/crematoria-in-ireland/)). The above fees may not include the cost of an urn, courier to return to baby's ashes in an urn, chapel service or burial of the urn. Other additional costs can include a funeral director, the grave digger, flowers and venues and refreshments at gatherings after the funeral.

### Assistance to Cover the Cost

#### *Life Insurance*

If bereaved parents have life cover, it will rarely cover the death of a child where the child died as a baby. INHA only identified Irish Life as explicitly stating in their policy that they would make a payment where a baby is stillborn. Other life insurance providers may make a payment at their discretion and interpretation of their policy.

#### *Supplementary Welfare Allowance Assistance towards Funeral Expenses*

In certain circumstances, where a family are unable to cover the cost of funeral expenses, they can make an application for an Exceptional Needs Payment under the Supplementary Welfare Allowance scheme. A staff member in the local Community Welfare Service office will make a decision on the application based on the parent's circumstances (Source: <https://www.gov.ie/en/publication/847761-recently-bereaved/#:~:text=Supplementary%20Welfare%20Allowance%20Assistance%20towards%20Funeral%20Expenses,-In%20certain%20circumstances&text=An%20Exceptional%20Needs%20Payment%20is,out%20of%20their%20weekly%20income>).

### Kildare County Council Sets Best Practice

We would like to commend Kildare County Council for introducing a policy to waive the fee for a single burial plot where a baby under 18 months old will be buried. If parents choose to purchase a family plot for their baby, the plot fee will be equally reduced. Alternatively, if parents choose to bury their baby in an "angels" plot, the council will also waive the fee.

## Best Practices in other Countries

### United Kingdom

*In Wales and England, bereaved parents no longer must pay for the funeral costs for their child after Labour MP Carolyn Harris set up a campaign after she needed a loan to pay for her eight-year-old son's funeral. The Welsh Government has establishment of a Children's Funeral Fund, which will waive the costs of burials and cremations for the families of children who die each year in Wales. The Welsh Government made £1.5m available to support local authorities and other providers of cemeteries and crematoriums (Source:*

*www.bbc.com/news/uk-wales-42096445). This funding will also be available to all other providers of cemeteries and crematoria in Wales who agree not to charge on the same basis.*

*In addition, throughout the UK, the Coop Funeral Franchise, provides funeral services free of charge up to the age of 18 years old (Source: <https://www.co-operativefuneralcare.co.uk/arranging-a-funeral/funeral-choices/childrens-funerals/>).*

*The free services provided are:*

- *All Funeral Director services to cover all aspects of the funeral arrangement, including the completion of all documentation and liaison with all third parties and appropriate advice, support, and guidance.*
- *Choice of coffin.*
- *Suitable vehicle for the parents and their child.*
- *Personnel to conduct the funeral.*
- *Use of the funeral home for service where available.*

### Poland

*In Poland, parents can apply for a funeral grant of €933 if their baby has died. To obtain this grant, bereaved parents need to present documents confirming the costs of burial and the right to obtain benefits (Source: <https://www.blizejprawa.pl/prawo-rodzinne/prawa-rodzicow-po-poronieniu/>).*

### Norway

*Bereaved parents in Norway can get up to €2458.71 towards the costs of their child's funeral from the State when a child is under 18 years old. There is no lower limit age of the child.*

## Our Asks

1. The Department of Housing, Local Government and Heritage must instruct all local authorities to introduce the same policy as Kildare County Council as a best practice standard.
2. The Department of Housing, Local Government and Heritage must instruct all local authorities to waive the fees for planning permission for headstones, where a baby will be buried.

3. A Children's Burial Fund should be established by the Department of Social Protection, so that local authorities can claim back the cost of the waivers outlined above.

## The State Records

### Stillbirth Registration and Certification

When a baby dies, recognition of their baby's existence is of utmost importance to bereaved parents. Bereaved parents want their baby to be acknowledged, named, and be counted.

In 1994, the Stillbirths Registration Act came into force. This legislation enabled the Government to recognise the birth of stillborn babies who were over 24 weeks gestation or who weighed over 500g. However, the stillbirth register is closed to the public and only the parents of the baby can have access to their baby's stillbirth certificate. It is alarming that siblings, grandparents, relatives, friends, and the future generation will only be able to have access to the stillbirth register once sufficient evidence has been produced that they are a relative of the child.

The Department of Social Protection has indicated that it is considering making the stillbirth register records open where bereaved parents have requested it and to keep those records closed for those who would prefer that option. The Department has also indicated that it is carrying out research on international best practice in relation to registration of babies who have died which will inform policy formulation in this area and potentially changes to the legislation.

### Best Practice in Other Countries

- *In Poland, registration of a baby who has died allows parents to obtain a birth certificate in the Civil Registry Office (see <https://eures.praca.gov.pl/en/looking-for-a-job-in-eu/you-are-an-eu-or-efta-citizen/living-and-working-in-poland/living-and-staying-in-poland/private-life>).*
- *In Germany, babies who are stillborn are recorded on the birth register with a mention of their stillbirth.*
- *In the Netherlands, a baby who is stillborn is recorded on the death register (See <https://www.government.nl/topics/registering-a-birth-and-name-of-child/rules-for-registering-a-birth>).*
- *In the Australian State of Victoria, there is no separate stillbirth register. Stillbirths are registered as births on a birth certificate that are marked stillbirth (see <https://www.bdm.vic.gov.au/births/stillbirths>).*

### Our Asks

1. The stillbirth register needs to be open with an opt-out for bereaved parents, keeping in mind that other qualified people such as hospital staff or coroners can register a baby as being stillborn without the parent's permission.
2. Parents whose babies are currently listed on the stillbirth register should be given the opportunity to have their babies placed on the birth and death register instead and to receive a birth and death certificate for their babies.

3. Parents should in future be given the option to receive a birth and death certificate for their baby who has died, so that babies who are stillborn can be registered on the birth and death register.

### Registration and Certification of Babies Born under 24 weeks and under 500g who Show No Signs of Life

If a baby dies before 24 completed weeks of pregnancy or weighs is under 500g, his or her birth cannot be entered into the Register of Stillbirths under the Stillbirth Registration Act 1994 (Source: <http://www.irishstatutebook.ie/eli/1994/act/1/enacted/en/print>).

Families who lose their child before 24 weeks of pregnancy or who weighs under 500g (showing no sign of life), do not receive any certification from the State that the baby existed and are left feeling that their baby did not count.

Bereaved parents must have the choice to officially register their pre-24 weeks baby. Registration should not be mandatory as some bereaved parents would find mandatory registration upsetting.

Giving parents the choice to register their baby who has died before 24 weeks gestation or who weighs under 500g, must be an integral part of good bereavement care and must be included as a standard in the HSE National Standards in Bereavement Care following Pregnancy Loss and Perinatal Death (Source: <https://www.hse.ie/eng/services/list/3/maternity/bereavement-care/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death.pdf>).

The National Perinatal Epidemiology Centre has also requested that it be notified of deaths in the early neonatal period (that is, babies born before 24 weeks gestation and weighing less than 500g). For 2017, 38 such deaths were reported by eight maternity units. Twenty-one of the 38 deaths occurred in babies born between 21- and 22-weeks' gestation and seventeen deaths occurred in babies born between 12-20 weeks gestation (Source: <https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinataIMortalityinIrelandAnnualReport2017.pdf>).

### Best Practice

#### *United Kingdom*

*The Civil Partnerships, Marriages and Deaths Registration Bill 2017-19 (Source: <https://services.parliament.uk/Bills/2017-19/civilpartnershipsmarriagesanddeathsregistrationetc.html>) requires the Secretary of State to prepare a report on how the law should change to allow registration of babies born under 24 weeks showing no signs of life. The Secretary of State is required to publish the report and to also make provision about the registration of stillborn deaths. It is expected that this report will be published in Summer 2021.*

## Our Asks

- The Irish Government needs to give the choice to bereaved parents to register their baby who weighs below 500g or is born before 24 weeks gestation (showing no signs of life) in the States records.
- Giving the choice to parents to register their baby who weighs below 500g or is born before 24 weeks gestation (showing no signs of life) in the States records must be included as a best practice standard in the HSE National Standards in Bereavement Care Following Pregnancy Loss and Perinatal Death.

### Abolishing Fees for Stillbirth and Birth/Death Certificates where a Baby has Died

Asking bereaved parents to pay for a copy of their baby's stillbirth certificate or baby's birth/death certificate on top of their loss is an unexpected added financial and emotional burden.

In Ireland, bereaved parents can get a free copy of their baby's stillbirth certificate at the time they register the stillbirth. All subsequent copies of a stillbirth certificate however cost €20. When a baby dies, recognition of their baby's existence in the States records is of great importance to bereaved parents and therefore some parents often opt to buy two copies of their baby's stillbirth certificate in case they lose the first one. Bereaved parents should not be expected to pay for this. In addition, the fees charged for a death certificate are €20 for a full standard certificate and birth certificate are also €20 and again bereaved parents should not be asked to pay.

### Best Practice in Other Countries

*From 1 April 2021, Suffolk County Council listened to the needs of bereaved parents and abolished stillbirth, birth and death certificate fees where a child under 18 has died*  
(Source: <https://www.suffolknews.co.uk/bury-st-edmunds/news/mum-s-plea-sees-stillbirth-registration-fees-abolished-9195425/?fbclid=IwAR0Lke5-ZRMqHAj-Z28yFitDCRpPWnMYITQ-aMjJShBxliA23hQDnct9vUA>)

## Our Ask

As a recognition of the difficult time that bereaved parents are experiencing after the death of their baby, the Department of Social Protection should abolish fees for second copies of stillbirths and birth/death certificates of babies who have died.



### Entitlement to Paid Leave when your Baby Dies

If a baby is born showing no signs of life and has a birthweight of less than 500g and a gestational age at delivery less than 24 weeks, alarmingly the baby's parents are not entitled to any leave and the decision to grant leave is at the employer's discretion. This situation is unacceptable, and the Government needs to review and remedy this situation as a matter of urgency.

Parents can be pressurised to return to work immediately following the death of their baby due to no entitlement to leave from their job. But it is obvious that no one is capable of working in the immediate aftermath of their baby's death. Some bereaved parents end up requesting sick leave from their local family doctor to give them some time off to cope with the trauma of losing their baby.

The introduction of the private member's *Organisation of Working Time (Reproductive Health Related Leave) Bill 2021*, by Senator Ivana Bacik is very welcome and we are very pleased to see that the bill has progressed onto the next stage having been discussed in the Seanad on the 24 May 2021.

This bill aims to offer bereaved parents whose baby is born showing no signs of life (with a birthweight less than 500g and a gestational age at delivery less than 24 weeks), entitlement to 20 days paid leave. It is a significant step in the right direction for the Irish Government but more needs to be done.

### Best Practices in Other Countries

#### *New Zealand*

*The New Zealand Parliament has recently unanimously passed legislation giving mothers and their partners three days of bereavement leave following a miscarriage or stillbirth. This was the result of Private Member's Bill in the name of Labour MP Ginny Andersen. The law change will now give women and their partners time to come to terms with their loss without having to tap into sick leave (source:*

[https://www.rnz.co.nz/news/political/439076/miscarriage-bereavement-leave-bill-passes-unanimously-in-parliament?ct=t\(EMAIL\\_CAMPAIGN\\_9\\_9\\_2019\\_10\\_26\\_COPY\\_03\)&fbclid=IwAR00jKzViRsH5SUIjM5q2ZLDapp\\_UDdMbn7dp7AO2XIDzIARBEL03IPaRJw](https://www.rnz.co.nz/news/political/439076/miscarriage-bereavement-leave-bill-passes-unanimously-in-parliament?ct=t(EMAIL_CAMPAIGN_9_9_2019_10_26_COPY_03)&fbclid=IwAR00jKzViRsH5SUIjM5q2ZLDapp_UDdMbn7dp7AO2XIDzIARBEL03IPaRJw)).

### Our Asks

We are asking the Government that the Irish Neonatal Health Alliance be a key stakeholder in the consultation process in relation to the progression of the Organisation of Working Time (Reproductive Health Related Leave) Bill 2021 to ensure that the needs of bereaved parents whose baby has died are fully considered.

### Changes to Maternity Leave and Paternity Leave

The Maternity Protection Acts 1994-2004, when a baby is stillborn and dies after 24th week of pregnancy or weighs is over 500g, the mother is entitled to take her full maternity leave. Paternity leave is also available to a parent when a stillborn baby dies any time after the 24th week of pregnancy or weighs over 500g.

However, maternity leave and paternity leave is not available to parents whose baby has died before the 24 week of pregnancy or weighs under 500g when the baby shows no signs of life at delivery. Sadly, parents can be pressurised to return to work following the death of their baby due to no entitlement to maternity leave and paternity leave. This must change.

### Our asks

- The Department of Social Protection needs to make maternity leave available for mothers whose baby is born showing no signs of life and is delivered before 24th week of pregnancy or weighs under 500g.
- The Department of Social Protection needs to make paternity leave available to a parent whose baby is born showing no signs of life and is delivered before the 24th week of pregnancy or weighs under 500g.

### Prevention of baby loss in a multiple pregnancy

Prevention of loss in a multiple pregnancy needs to be urgently addressed by the Irish Government. This is because the research shows a consistent association between baby loss and multiple pregnancy (Source:

<https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinatalMortalityinIrelandAnnualReport2017.pdf>)

Shockingly, there are no consistent standards for multiple births across all 19 maternity units in Ireland with each hospital clinical governance board self-selecting which clinical guidelines to use, such as:

- The NICE guidelines for twin and triplet pregnancy (NG137) and its quality standards [Source: <https://www.nice.org.uk/guidance/ng137>] or
- the HSE Clinical Practice Guideline: Management of Multiple Pregnancy [Source: <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/clinical-practice-guideline-management-of-multiple-pregnancy.pdf>].

### Best Practice in the UK

*NICE guidelines for twin and triplet pregnancy (NG137) and its quality standard (SQ46) were set up by the UK Government and are mentioned in its Health and Social Care Act 2012 to advise the Department of Health and Social Care (Source:*

*<https://www.legislation.gov.uk/ukpga/2012/7/part/8>). The NHS Long Term Plan commitment to roll out the “Saving Babies Lives Care Bundle”, recommends using NICE, across every maternity unit in England during 2020.*

*NICE has been adopted in the UK as best practice in preference to seeking the advice of solely independent membership organisations of medical professionals. Its evidence is developed after extensive, documented review of the literature that has gone to public consultation so that representative organisations also have an opportunity to feed into the process.*

*The report called “NICE works” produced by the UK charity Twins Trust in 2020, demonstrates through its Maternity Engagement Project that increased adherence to the NICE Quality Standard on Multiple pregnancy (QS46) is linked to improved outcomes for women and their babies (Source: <https://twinstrust.org/static/afcc44b3-776e-4341-8a16e9bd990c3425/NICE-works-final-report.pdf>). The report shows that in just two years after NICE QS46 was followed in 27 maternity units in the UK, there was a:*

- 6% reduction in stillbirths
- 18% reduction in neonatal deaths and
- 23% reduction in neonatal admissions.

*It found that if all units followed NICE QS46 across the UK:*

- 100 babies’ lives could be saved every year,

- *Neonatal admissions could be reduced by 1,308 and*
- *All of this could save the NHS £8million every year.*

*All 27 maternity units who took part in the Maternity Engagement Project made changes to their antenatal care and these changes were a zero cost or a low cost.*

*Initial funding for the project from the UK Department for Health and Social Care was £400,000 over 3 years. This covered everything from recruitment costs to staff costs and the time needed to establish the processes, tools, and resources for maternity units to implement NICE QS46.*

### **Systems Analysis Review**

In Ireland, a Systems Analysis Review (2019) by the RCSI Group produced the following recommendations which align with NICE clinical guidelines:

- i. Revise the Standard Management of Multiple Pregnancy Guidelines to include antenatal admission of women with multiple pregnancy for any reason.
- ii. On completion, the policy must be circulated, and appropriate training and education given.
- iii. Audits must be carried out at regular intervals to monitor if full compliance with this guideline has been achieved.
- iv. All antenatal admissions whether admitted for obstetric or non-obstetric reasons should have a plan of care described for monitoring of fetal wellbeing.
- v. The practice of recording Fetal Heart Heard (FHH) should be discontinued and instead the numbered rate of the fetal heart beats should be recorded to ensure identification of multiple fetal hearts.
- vi. Method of auscultation (For example: Pinard: a handheld device for listening to fetal heart rate. Sonicaid: a handheld doppler for measuring fetal heart rate. CTG: Cardiotocograph or electronic fetal monitor for measuring fetal heart rate and uterine contractions in labour) should also be documented at every assessment of fetal heart.
- vii. In the event of difficulty in fetal heart auscultation the documentation in the healthcare record must reflect assistance sought and the outcome recorded.
- viii. Recommendation to the Institute of Obstetricians and Gynaecologists to generate a guideline with respect to fetal wellbeing for antenatal monitoring to include admission for non-obstetric issues.

### **Velamentous Cord Insertion**

The prevalence of velamentous cord insertion and screening in twin pregnancies has been recognised in the Irish multicentre Research Study ESPriT (Source: Etaoin M. Kent (2011) *Placental cord insertion and birthweight discordance in twin pregnancies: results of the national prospective ESPriT Study*, American Journal of Obstetrics & Gynecology

[www.ajog.org](http://www.ajog.org)). Checking the placental cord insertion is recommended in numerous international guidelines including International Society of Ultrasound in Obstetrics & Gynaecology (ISOG), American Institute of Ultrasound in Medicine (AIUM) and Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and yet it is not checked in many maternity hospitals in Ireland as a best standard practice.

In addition, as the incidence of velamentous cord insertion is common in twins especially in MCDA twins where its prevalence is 1:9, Dublin District Coroner has also recommended that the placental cord insertion site must be checked and recorded at the time of the anomaly scan in all MCDA twins.

### **Our Asks**

- The Department of Health needs to ensure that the revision of the HSE national clinical practice guideline for the management of multiple pregnancy that is currently underway by the National Women and Infants Health Programme and the Institute of Obstetricians and Gynaecologists include the recommendations in the Systems Analysis Review outlined above (and not only be rolled out in the RCSI Hospital Group of maternity hospitals which carried out the review).
- The HSE national clinical practice guideline for the management of multiple pregnancy needs to be put out for public consultation, so that representative organisations can feed into the consultation process.
- The Department of Health must instruct that all 19 maternity units in Ireland use the revised HSE national clinical practice guideline for the management of multiple pregnancy rather than self-selecting which one to use and / or developing their own guidelines.
- Checking of placenta cord insertion needs to be included in the anomaly scan clinical guidelines screening checklist which is going to be developed by the National Woman and Infants Health Programme and the Institute of Obstetricians and Gynaecologists.
- The Department of Health needs to fund an initiative that will enable the 19 maternity units in Ireland to be audited and supported to implement the HSE national clinical practice guideline for the management of multiple births. It will cost considerably less than in the UK as learnings from the Twins Trust Maternity Engagement Project can be used, for example, the Twins Trust Care Pathway, assists with the implementation of the NICE Quality Standard on Multiple Pregnancy (QS46). This resource is freely available and are an easy way to improve ante-natal care [Twins Trust (2020) Multiple Pregnancy - Care Pathway <https://twintrust.org/uploads/assets/510d7947-8a35-4272-bbd477be5e9ac834/Multiple-Pregnancy-Care-Pathway-for-Parents.pdf>]. Free online training to healthcare staff is also already available through Twins Trust at: <https://twintrust.org/healthcare-professionals.html>. Irish healthcare professionals can already log on to access free CPD videos covering antenatal and intrapartum best practice and resources from multiple specific study days. The Department of Health needs to provide €300,000 over 3 years initial funding for the initiative. This

will cover recruitment costs for staff, staff costs and development of processes, tools, and resources. The Department should also provide €8,500 per maternity unit for an audit to be carried out with 6 audits being carried out in the first year, 6 in the second year and 7 in the third year.

## Emotional Supports to Bereaved Parents in the Community

In its policy document “Specialist Perinatal Mental Health Services: Model of Care for Ireland” the HSE recognises that the death of a baby can trigger a need for mental health supports for bereaved parents (Source: <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>).

The HSE’s National Standards in Bereavement Standards following Pregnancy Loss or Perinatal Death also says that level two bereavement care will be of benefit to some bereaved parents so that they have an opportunity to talk about what they have gone through (Source: <file:///C:/Users/conno/Desktop/INHA%20Work/Nat%20Std%20in%20Bereavement%20Care/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death.pdf>).

In the Department of Health’s “Consultation on the development of a National Maternity Strategy” several respondents said that they would like to see greater access to counselling services and follow up supports and it was noted that “no funding is available to provide counselling to those who suffer stillbirth” (Source: <https://assets.gov.ie/18838/eb7036e9223445449fd15e647723b6c2.pdf>).

In addition, the National Maternity Strategy 2016-2026 makes a commitment that “all couples who experience pregnancy loss should be supported psychologically by hospital staff and have access to bereavement counselling either in a hospital or primary care setting” (Source: <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>).

Standard 1.8 in HIQA’s National Standards for Safer Better Maternity Services states that “Maternity service providers ensure additional supports are in place for women and families who experience bereavement or pregnancy complications and that “If you experience pregnancy loss, perinatal death or pregnancy complications you receive the care and emotional support you need from the time this becomes known (Source: <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>).

It is obvious that parents who experience loss of their baby may require specialist emotional support triggered by intense grief and the trauma of their experience. However, despite the Government policy commitments outlined above this support continues to be unavailable, inaccessible, or inappropriate for many. Bereaved parents whose baby has died are falling through the gaps between policy and funding and are being overlooked.

Many bereaved parents need to seek additional supports such as counselling outside of the support that they receive from family and friends as parental grief can bring about particular challenges. Some bereaved parents seek organised supports from baby loss organisations which may involve professional counselling but many of these organisations, operate on a voluntary basis and do not receive State funding and struggle to provide such supports.

The Government needs to take action to ensure that all parents who experience loss of their baby who want to avail of specialist emotional support can access it, at a time and place that is right for them, free of charge, wherever they live. The Government must further develop and implement a policy on mental health needs for bereaved parents when their baby has died. This assessment needs to inform future mental health policy.

Representative organisations, including the INHA, and bereaved parents must be involved in the research as key stakeholders. This should be led by the Department of Health, as part of mental health policy and strategy.

### **Best practice in Other Countries**

*The NHS England and NHS Improvement announced in April 2021 that more mental health support for expectant and bereaved mothers. Research carried out by SANDS UK, the leading stillbirth and neonatal death charity in the UK ([www.sands.org.uk](http://www.sands.org.uk)), alongside other pregnancy and baby loss charities in the UK, found that 60% of bereaved parents felt they needed specialist emotional support in the community, but were not able to access it on the NHS (Source: <https://www.england.nhs.uk/2021/04/dedicated-mh-services/>). Thousands of new, expectant mothers and bereaved mothers will now receive help and support for mental health problems through 26 new dedicated hubs which are being set up across the UK. This is part of the NHS Long Term Plan (Source: <https://www.longtermplan.nhs.uk/>) and it is planned that every area will have a hub by April 2024. It is estimated that it costs the NHS and social care sector £1.2 billion per year where women do not access high-quality perinatal mental health services.*

### **Our Asks**

- Government policy on mental health needs a coherent plan for parental bereavement care and supports to parents whose baby has died with a review of resources required which are benchmarked against existing best practices and standards. This plan must include an assessment of the capacity of voluntary sector to provide sufficient counselling to meet needs of bereaved parents in an appropriate and evidence-based way.
- The Government needs to follow the best practice in the UK by rolling out of mental health support services for expectant and bereaved mothers through new dedicated hubs across the country.



## Covid 19 and Baby Loss

The INHA have been informed that all maternity hospitals are continuing to provide bereavement care to parents who experience death of their baby as we continue to live with the pandemic. We very much welcome this decision by the Government. We also commend the Government for ensuring that the partners or a support person of women whose baby has died have unrestricted access during their time in hospital. It is also positive to read in a HSE briefing note to the Joint Committee on Health that the management team in each maternity unit in Ireland has confirmed the above guidance has been implemented when visited by the Oversight Group of the *HSE National Standards in Bereavement Care following Pregnancy Loss and Perinatal Death* in August and September 2020.

The Institute of Obstetricians and Gynaecologists has also issued COVID-19 Guidance for Maternity Services (May 2020) (Source: [Maternity/Women and Infants - Covid-19 HSE Clinical Guidance and Evidence - HSE Library Guides at Health Service Executive \(drsteevenslibrary.ie\)](#) which orders that “Diagnosis, investigation and management of pregnancy loss should continue as much as possible in accordance with the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death” during Covid 19 and that “Each institution should have an agreed protocol for same to ensure that bereavement care is not unnecessarily compromised’. This guidance also makes a recommendation that “Isolation and infection control policies associated with COVID-19 infection should be applied in pregnancy loss situations with a risk/benefit analysis and evidence base so that staff can continue to provide the highest standard of compassionate supportive care”.

In addition, the guidance also points out that “the importance of the presence of a partner/support person during what is finite time should be protected” but does however state that they cannot be present or be a support person if they have been confirmed or suspected COVID-19 positive. The British Association of Perinatal Medicine (BAPM) nonetheless recommends that “everything possible, should be done to achieve parental presence and participation in care, even for Covid-19 positive parents” (Source: [https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2\\_assets/files/740/COVID\\_FAQ\\_06.11.20.pdf](https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/740/COVID_FAQ_06.11.20.pdf)) and the INHA endorse this recommendation. Partners who test positive for Covid 19 must be facilitated to make memories remotely with their baby when their baby is going to die or has died. This might include giving the partner the name of person that they can contact on the phone to get information about their baby and the mother and to facilitate virtual access for families using from example V-Create, Skype or Facetime. This will allow partners to also create precious keepsakes of their baby’s short life and their time with them before and after they die.

The Government has given advice to maternity hospitals in Ireland that a partner can be present at the 20-week anomaly scan but alarmingly, some hospitals have chosen not to do this (Source: <https://www.thejournal.ie/maternity-hospitals-covid-restrictions-5319863-Jan2021/>). This means that several women will be receiving bad news about their pregnancy during their 20-22 week anatomy scan on their own without the support of their partner. Birth partners are advocates and a critical component of the pregnancy and birthing process and they must be treated as such.

## Our Asks

- The British Association of Perinatal Medicine (BAPM) recommends that “everything possible, should be done to achieve parental presence and participation in care, even for Covid-19 positive parents” (Source: [https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2\\_assets/files/740/COVID\\_FAQ\\_06.11.20.pdf](https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/740/COVID_FAQ_06.11.20.pdf)) and we endorse this recommendation. The Institute of Obstetricians and Gynaecologists COVID-19 Guidance for Maternity Services (May 2020) needs to be revised so that this recommendation is included, and partners can make “virtual” memories with their baby who has died or will die.
- The Department of Health needs to instruct hospitals to allow pregnant women to have their partners present throughout all elements of pregnancy, labour, and birth appointments, so that women are not being forced to go through labour alone or hear devastating unexpected news about diagnosis of a life limiting condition or that their baby has died in utero or during delivery without the support of their partner.

## More information

If you would like any further information on our concerns and asks outlined above, please contact:

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