REPORT

Centre for
Mental Health

Life after loss

An economic evaluation of specialist counselling after baby loss

Nick O'Shea

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Contributors

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Petals
The Baby Loss Counselling Charity

Foreword

There can be few more tragic and distressing circumstances to face in life than the loss of a baby. It is a loss that devastates those who go through it and has a profound, lifelong impact on the parents of the lost child. It is a form of bereavement that has not always been understood or accepted as well as it should have been. As a result, the suffering and the trauma are made all the worse.

Centre for Mental Health's mission is to challenge inequalities and gaps in support and to highlight practical ways of meeting people's needs. We have been able to demonstrate the benefits of supporting women experiencing mental health difficulties during pregnancy and after they have given birth. And as a result of that work and the efforts of campaigners across the country we have seen unprecedented investment in perinatal mental health services across England.

But when women lose their babies, when they die in the most tragic and traumatic circumstances, effective help isn't always there. While health workers do their best to help, and bereavement support is offered in the immediate aftermath, long-term support is still not routinely offered on the NHS to those who have experienced the death of a baby.

The service offered by Petals, the baby loss counselling charity, may help to fill that gap. While nothing can take away the pain of loss, its counselling service can help parents to process what has happened to them and to rebuild their lives in the context of that tragedy.

We are honoured to have had the opportunity to work with Petals to carry out this economic evaluation of their vital work. Putting a monetary value on our health is never easy or straightforward. And the primary reason for any health intervention is to improve our health, not to save money. But time and again we find that doing the right things for people also makes sound economic sense in a world where limited funds make hard choices a necessity every day.

I hope that this report will prompt local and national action to ensure that women and their partners get the emotional and psychological support they need when they have lost their baby. One of the great values of our NHS is its compassion and its response to human suffering. I believe that it can and will see the need to invest in support that can make such a profound difference to people's lives in their darkest days.

Sarah Hughes
Chief Executive, Centre for Mental Health

Executive summary

This report presents an evaluation of the financial costs and benefits resulting from counselling provided by Petals, the baby loss counselling charity, and it projects the impact of a national scheme.

Petals' support programme helps the parents of babies who are stillborn or who die within 28 days of birth to cope with the trauma of sudden, unexplained and tragic loss. Such losses can affect any family and are devastating.

The evaluation calculates that national provision of counselling to 4,822 mothers would cost £3.17m per annum. This would create a national safety-net of support to help parents at this immensely difficult time. No such service currently operates across England and Wales.

The benefits of counselling include improvements to health, relationships and employment.

Using quantitative measures only and focusing exclusively on the specific costs to government in terms of benefit payment, health care and social services, the evaluation concludes that investing in a nationwide service would result in a net saving to government of £8.6m per annum.

On average, £1 invested in Petals will return, net, £2.71.

The reasons for this are:

- The provision of counselling is relatively cheap - £69.70 per session (including on-costs);
- The costs of unresolved trauma are high in terms of health care and benefit payments;
- Counselling is shown to be effective at reducing the effects of trauma.

The calculations in this evaluation are based on quantitative evidence, and conservative assumptions are always employed. We also focus on a small range of factors that impact on government spending, rather than taking a broad and all-encompassing approach. The financial impact on the parents themselves is also considered – for example the cost of relationship breakdown – but not included in our net savings calculations.

In short, counselling is inexpensive, effective and reduces government expenditure. A national scheme to help people who are faced with the tragedy of loss during pregnancy or birth would benefit parents, families and government. This is a rare instance where fiscal prudence and compassion converge.

Introduction

Petals – The baby loss counselling charity

In 2017, there were 4,822 stillbirths or deaths of babies within 28 days of birth in England and Wales. For many parents, these tragic circumstances result not only in grief but also in trauma.

Counselling by Petals aims to help parents to understand and cope with that trauma. Specifically:

- To engage the parent or parents with, and resolve as much as possible, any enduring emotional effects resulting from experiences of traumatic loss
- To coach and guide them through the grieving process
- To negotiate the reconciliation of broken expectations with a new, unexpected reality and future.

Trauma-based counselling is distinct from bereavement care. The National Bereavement Care Pathway supports parents during the immediate aftermath of a death: it helps parents to make informed decisions about their baby, gives them the opportunity to make memories and provides information on further support in the community. Petals, on the other hand, provides community support in the period after loss, giving several weeks of counselling to parents.

Provision of this type of support is rare. As the most recent Evaluation of the National Bereavement Care Pathway (Donaldson, 2019) identified:

> *In terms of emotional and psychological support in the community, parents revealed a large unmet need. This is not within the scope of the NBCP but clearly has an impact on the recovery of bereaved parents, several of whom felt they did not receive any aftercare. Some put this down to lack of services in the community or not being considered ill enough to access psychological support.*

Petals responds to this need with its six-session counselling programme, which currently takes referrals from seven hospitals. The organisation is funded through a patchwork of different funders with grant-makers contributing extra funding to NHS contracts that would otherwise be loss-making for the charity.

This report evaluates the case for a larger and more robust funding mechanism that would enable nationwide support for bereaved parents.

Jenny & Ian's story

Jenny enjoyed a healthy pregnancy with Bea, but at 20 weeks she was in the breach position and remained in this position for the rest of pregnancy. At nearly two weeks overdue, labour began and progressed well until delivery of Bea's head was delayed. The consultant wasn't called to help until it was too late. Staff tried to resuscitate Bea, but tragically she lost her life.

In the months that followed, Jenny and Ian focused on preparing for the inquest into Bea's death and looking after their two-year-old son. Jenny described how difficult it felt to talk to people about what happened and how she avoided expressing emotions – she would compose herself, tell people what happened, and then observe their upset – this was how she coped. She wanted people to ask, to talk about it – it felt better to talk – but many avoided it.

Jenny described feelings of isolation and disconnection with her family and friends. She sought private counselling but found that she dreaded going, so decided to stop.

The inquest into Bea's death took place eight months later, resulting in the Coroner requesting a national review into breach delivery births. The Chief Executive at Petals watched the news coverage of this and felt compelled to 'reach out' to Jenny and Ian to offer Petals counselling support.

At their first counselling session, Jenny and Ian presented themselves with dignity and polite caution – Ian clearly protective of his wife and wanting to understand how counselling was going to help them, sceptical that anything could really make a difference to their devastation. When asked why they had decided to come to counselling, Ian explained "we just can't see a way out of this – we want more children, but I cannot imagine putting Jenny through this again. Right now, neither of us feel we will ever be able contemplate having another baby, and that is heartbreaking for us."

The early sessions of counselling focused on the events of Bea's birth and death. It was clear that Jenny and Ian had both become versed in telling their story in a factual manner. Through the development of empathy with the counsellor, they were able to focus on their actual memory of that day, connecting with all their senses and feelings that had been blocked by their own natural, self-protective reaction at that time. Witnessing each other open up in this way had a profound effect on them both, as they realised how differently they had experienced the same events.

As the sessions progressed, Jenny seemed to grow in confidence and courage. She said she was recognising how she actually felt, rather than thinking about how she should feel, and this meant she could cry and be sad, and that felt good. She described a yearning for Bea deep within herself – she described it as a physical pain, but one that she wanted to feel, as this connected her with her daughter.

At the fifth session, Jenny came to a significant realisation: "I suddenly realised I couldn't actually change what had happened and that everything we had been doing over the months after losing Bea, making sure our concerns were taken seriously and trying to achieve change through the inquest, wasn't going to bring Bea back. This reality hit me and suddenly I knew Bea was dead – I could accept it."

In a letter to Petals following this, Jenny wrote: "I feel the tremendous benefits of learning to communicate my feelings and this is something I'll certainly try to carry forward throughout life. As we moved through our sessions... I was learning who I was again, that life had profoundly changed but I was growing, and learning so much about myself. I'm now starting to feel happy again."

Names have been changed to protect anonymity

The impact of trauma

In recent years, there has been growing recognition of the risks and vulnerabilities of the perinatal period. For example, *The Five-Year Forward View for Mental Health* identified perinatal mental health provision as a priority area for improvement (NHS England, 2016). The NHS has responded by investing £365m in services over five years (NHS England, n.d.). However, much of this funding has been directed towards increasing provision of specialist community perinatal mental health services and inpatient mother and baby units to support mothers who experience mental ill health during and after pregnancy. While these services are vital, they are not designed to support parents affected by perinatal trauma and loss.

Best practice guidelines recommend that counselling should be offered to these parents (RCOG, 2010; Redshaw, Rowe & Henderson, 2014; National Maternity Review, 2016; Bakhbakhi *et al.*, 2017; Ladhani *et al.*, 2018). However, in the UK, provision of this support is patchy. For example, Mills *et al.* (2016) conducted a survey of maternity units in England in 2012. Of the 138 units that responded (73%), only 40% reported having formal written guidelines on how to support mothers who had experienced stillbirth or neonatal death; and, "[w]here guidelines existed, monitoring and surveillance appeared to be accorded more emphasis than emotional support and psychological care." A recent study on maternity care in the UK concluded that, "despite the best intentions of staff who care for bereaved parents, care after stillbirth is often not as good as it could or should be" (Siassakos *et al.*, 2017). This is equally true for other forms of perinatal trauma and loss. As a result, there have been calls for improvement to the support offered to bereaved and traumatised parents (National Maternity Review, 2016).

The costs of neonatal deaths and stillbirths

It has been estimated that a stillbirth costs between 10% and 70% more than a live birth. (Heazell *et al.*, 2016). The economic burden of perinatal trauma and loss is borne not only by the NHS, but also by families and wider society. The extent and nature of these costs are still largely unknown, owing to the absence of systematically collected national data (Heazell *et al.*, 2016). However, using innovative methodologies, some studies have attempted to redress this situation.

Costs identified by research include but are not limited to:

- Health care for the mother, the baby and subsequent babies
- Psychological support for the mother and other family members
- Post-mortems and investigations
- Funerals
- Litigation
- Payment of damages
- Payment of benefits
- Absence from work of parents and of health care professionals affected by the birth
- Reduced productivity at work (Ogwulu, et al, 2015; Heazell *et al.*, 2016; Campbell *et al.*, 2018).

A recent study estimated the costs associated with 3,252 stillbirths in 2014 in the UK. These included, among others:

- £13.6m in health and social care costs
- £12.5m in productivity losses of parents and health care professionals
- £2.5m in NHS litigation costs
- £1.8m in funeral-related costs (Campbell *et al.*, 2018).

The authors note that these figures are conservative estimates; moreover, they do not include the costs of perinatal losses and trauma other than stillbirths. If, for example, neonatal deaths were factored in, the costs would be significantly higher.

Sally's story

Sally had been in an on-off relationship which ended when she discovered she was pregnant. As she was 38 years old, Sally felt this might be her only opportunity to become a mum and decided to continue with the pregnancy with the support of her mother.

At 41 weeks of a trouble-free and low-risk pregnancy, Sally started labour during the night and went to the hospital with her mum as labour-partner. Baby Josie was born the following morning with no signs of life, and despite efforts to resuscitate, was confirmed stillborn shortly after delivery.

Sally was signposted to Petals by the maternity staff immediately. At the initial counselling session, Sally was accompanied by her mother who was keen to tell the story of events. Sally sat quietly without emotion as her mother expressed her rage. When the counsellor tried to engage with Sally, she gave short responses saying it all felt unreal, as though this had happened to someone else. She said she felt numb.

As the counselling relationship developed, Sally was able to recognise that pretending things hadn't happened was a familiar coping strategy she had developed to deal with a number of abusive experiences she had been through in her life. She carried a heavy sense of shame and this was her overwhelming feeling again – that she was just not good enough or worthy of being a mother. She strongly felt the absence of a partner and the stigma of being a single parent. Sally was now struggling with work and following discussion with the counsellor, made an appointment with her GP where she was signed off work for a few weeks.

With time and space to connect with her reality, it was clear that Sally was starting to feel the magnitude of her loss and this rapidly seemed to overwhelm her. The counsellor noticed a fundamental change in her presentation at sessions – she was now eager to talk and her emotions flowed out of her. Sally wanted to understand more about what was happening to her, to meet other women who had suffered stillbirth. The counsellor was able to link her with other bereaved parents and this really helped.

At the six-session review, Sally and the counsellor agreed to extend the number of sessions to nine. The counsellor noticed the relief this brought Sally and she seemed to relax further into the sessions, determined to maximise the opportunity for reflection and learning. She had requested a further meeting with the obstetric consultant to ask more questions about what had gone wrong, and had also started to explore options for IVF treatment.

Sessions 7 and 8 were used to really examine and process the moments where it seemed trauma had occurred for Sally during the birth. The moments when her baby emerged and was rushed to the other side of the room as the crash team swarmed in were now coming into focus for Sally, as was her mother's expression as she saw baby Josie. Until this point, Sally had not remembered any of this, and suddenly, in the intimacy of the counselling room, it was coming back to her. She physically shook as the memories emerged, she sobbed from her gut, and then she sat very still, and silent.

In session 9 a lighter, brighter Sally walked into the counselling room. She talked about the phased return to work she had negotiated with her employer and how she now felt ready to engage with her life again. Sally and her counsellor agreed to end their work together at this point, with the proviso that Sally would get in touch if she felt the need.

Sally is a pseudonym for an amalgam of clients supported by Petals

Mental ill health – depression and anxiety

The association of perinatal trauma and loss with increased levels of depression and anxiety is well-established. However, the extent of this increase is unclear with different studies presenting findings that differ in terms of whether they relate to: symptoms of depression and anxiety vs. disorders; subjective measures vs. clinical diagnoses; high/middle income countries vs. low income countries; stillbirths vs. miscarriages; etc. These differences limit the commensurability of the findings presented below.

Large-scale systematic reviews of the literature have found the prevalence of perinatal depression and anxiety among the general population to be approximately 10% (Dennis, Falah-Hassani & Shiri, 2017; Woody *et al.*, 2017).

The UK-based National Perinatal Epidemiology Unit surveyed 720 women and their partners whose babies were stillborn or died as a newborn. They found that, nine months after their loss, approximately 30% of mothers and 20% of fathers were suffering from anxiety and/or depression (Redshaw *et al.*, 2014).

An Australia-based study found the prevalence of postnatal depression to be two to three times higher among women who had experienced a traumatic birth than that reported for the general population (Gamble *et al.*, 2005).

A US-based study of women who had experienced a stillbirth compared with women who had delivered a healthy live birth found that depression was more likely with a stillbirth (14.8% vs. 8.3%) (Gold, Leon, Boggs & Sen, 2016).

In terms of costs, the mean cost of parental anxiety and depression to the NHS has been estimated at £549 per stillbirth (Campbell *et al.*, 2018).

Physical health

Perinatal trauma and loss may affect the physical health of both the mother and her subsequent children. The mother may be more likely to experience harm, illness or more invasive procedures, such as an emergency caesarean section, during pregnancy and/or birth. And, sadly, a mother who has experienced perinatal trauma or loss in one pregnancy is at increased risk of experiencing perinatal trauma or loss in a subsequent pregnancy; therefore, for future pregnancies and births, she will have had additional health care needs (Lamont, Scott, Jones & Bhattacharya, 2015; Wojcieszek *et al.*, 2016; Fockler, Ladhani, Watson & Barrett, 2017; Ladhani *et al.*, 2018; Malacova *et al.*, 2018).

The physical health consequences of perinatal trauma and loss generate costs that include but are not limited to:

- Treatment of any physical harm or illness suffered by the mother;
- Longer hospital stays and absences from work required for the mother to recover;
- Lost productivity of partners or other care givers supporting the mother;
- More specialised care required for subsequent pregnancies;
- More monitoring and treatment needed for subsequent pregnancies;
- Additional 'standard' antenatal care if the mother conceives again within 12 months of the loss – a pregnancy that is unlikely to have occurred, if the previous pregnancy had not resulted in loss (Fockler *et al.*, 2017; Campbell *et al.*, 2018; Heazell *et al.*, 2019).

Employment

A review of the economic and psycho-social consequences of stillbirths found that:

- 10% of bereaved parents remained off work for six months;
- 38% of mothers and 21% of partners reduced their hours;
- Even after normal hours had been resumed, productivity was affected, with estimates of 26% of normal work after 30 days increasing to 63% after six months (Heazell *et al.*, 2016).

Stephanie & George's story

Stephanie and George have been married for 12 years. They both have busy careers and had planned to start a family once they were in a secure financial position with the family home prepared. They had not expected to struggle with conception, and after four early miscarriages, decided to embark on the journey of IVF to start their much-wanted family.

In their late thirties, they opted to have two embryos transferred at the IVF clinic and were delighted to discover they were carrying twins at an early scan. The pregnancy progressed relatively well until the 25th week, when Stephanie suddenly discover her waters had broken whilst at work.

Later that day their baby boys were delivered; baby Joseph was stillborn, and baby Maxwell was rushed to Neonatal Intensive Care for support. Both Stephanie and George described this day as the most frightening experience of their lives.

Stephanie and George came to counselling for the first time three weeks later. They had spent most of their time watching baby Maxwell as he fought for his life in NICU. As they began to explain the events of the past weeks, they seemed shell-shocked, disorientated and bewildered. The counsellor was struck by the disconnection between them – and when she reflected this to them, they agreed – Stephanie commented 'I don't know who I am anymore' with a haunted expression on her face. George talked about the practical aspects of arranging the funeral for baby Joe: he wanted to make sure he got it right, and that Joe was not forgotten.

The counsellor arranged to see the couple weekly at a set time and this became part of their daily ritual of coming to the hospital to be with Maxwell, hoping and praying that he would gain strength to one day come home so they could become 'real' parents. They chose to come to sessions together, and agreed that this was the only time they could properly talk together – it became a very important space for them both. The counsellor ensured that there was time to talk about both of their children, being with life and death and processing their different feelings as they emerged, encouraging them to really listen to each other.

As the weeks passed and Maxwell continued to grow, the couple dared to believe they might take him home. The work within the sessions changed as their responses to this reality emerged – George expressed his excitement and relief; Stephanie explained how frightened she felt. How would she cope without the team of professionals around? How would she be able to sleep, and trust that Maxwell wouldn't die? The traumatic impact of the whole experience began to surface for Stephanie as the counsellor helped her process her terror. George and Stephanie agreed that it might be beneficial for Stephanie to have some sessions on her own with the counsellor.

Over the following three weeks, Stephanie revisited the trauma she had experienced. The counsellor supported her to absorb and come to terms with her babies' premature birth, and becoming the mother of two boys, one who is with her and one who has died.

Three months after his birth, baby Maxwell went home with Stephanie and George. The three of them returned to the hospital for a further two counselling sessions as the counsellor supported them through this adjustment.

Stephanie and George are pseudonyms for an amalgam of clients supported by Petals

Summary

Perinatal trauma and loss have far-reaching and long-lasting consequences. There is strong evidence that they lead to a range of negative psychological outcomes both for mothers and for their partners; and there is some evidence that they are associated with poorer physical health outcomes, especially in subsequent pregnancies. They may also negatively affect relationships and employment.

In addition to their impact on health, wellbeing and day-to-day functioning, perinatal trauma and loss are financially costly for the NHS, individuals and society. They negatively affect parents' and health care professionals' employment and productivity. They also generate costs in the form of, for example, specialised care, benefit payments, litigation and funerals. These negative outcomes and costs are widely recognised in the literature, even if the data are insufficient to determine their exact scale and extent.

Less is known, however, about how these negative impacts can be mitigated. Psychological support shows promise: it is wanted and valued by parents; it is widely recommended in best practice guidelines; and, where evidence does exist, it indicates that these interventions are associated with positive changes in meaningful outcomes. But more research is needed before any firm conclusions can be drawn.

Costs and benefits

Cost projections - a national scheme

The cost of a counselling session delivered by Petals, including office and management costs, is £69.70. A complete course of counselling is six sessions, bringing the total cost to £418.20. Petals' records show that 57% of parents who use their counselling service go on to request a further six sessions once they are pregnant again. Again, six sessions cost £418.20 to provide.

In 2017, there were 4,822 stillbirths or deaths of babies within 28 days of birth. This means that there were approximately 9,644 parents who suffered this traumatic event. Petals offers counselling to all parents referred, either individually or as a couple. Individual counselling is predominantly taken up by mothers. Therefore, the costing assumption is one programme of counselling per episode of grief. In 2017, this is 4,822 courses of six sessions, plus a further programme of six sessions for the 2,749 women who would have further counselling when they became pregnant again.

The cost of providing 7,560 courses of counselling, based on the Petals costings, is £3.17 million per year. This assumes a straight-line expansion is possible based on existing expenditure and ignores any economies or diseconomies of scale. It includes office, management, supervision and on-costs.

To provide individual counselling to both parents (9,644 mothers and fathers) would cost £6.34 million.

The economic case for counselling

Chapter 1 identified a range of negative outcomes associated with bereavement and loss. These include:

- Relationship breakdown;
- Increased mental ill-health;
- Being unable to return to work.

This section examines the impact of Petals' counselling on its recipients to understand if savings from improved coping strategies for loss and bereavement outweigh the costs of delivery.

Mental health

Pregnancy and birth are times when women are more likely to experience mental illness. Earlier work by Centre for Mental Health with the London School of Economics (Bauer *et al.*, 2014) found that the prevalence of antenatal depression and anxiety was 7.4-14.8% and 11.8-15.3% respectively, and that of postnatal depression and anxiety was 7.4-12.8% and 8% respectively. These are figures for a typical pregnancy and summarised in Table 1.

Table 1: Costs to the Public Sector by health problem (from Bauer *et al.*, 2014)

	Cost to public sector per mother	
Identified condition	**2014 estimates**	**2018 estimates (adjusted for inflation)**
Perinatal depression	£1,688	£1,856
Perinatal anxiety	£4,320	£4,751

The stress of pregnancy and birth multiplied by trauma and grief leads to significant mental health challenges amongst parents who have suffered the loss of a baby. An observational study of Petals' clients [personal communication] found that, pre-counselling, 67.4% of the 230 women they saw were classified as having clinical needs, as assessed by Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM). Following counselling, only 10% of women still had clinical needs according to this measure; 57.4% had improved to such an extent that their scores corresponded to those of a non-clinical population.

Using the costs of health care and the outcomes from counselling observed, we model the financial impact that would be expected if costs and benefits could be replicated nationally. Figure 1 describes the possible scenarios and Table 2 identifies the costs of each and the potential for savings associated with them.

Figure 1: A theoretical model for financial projections

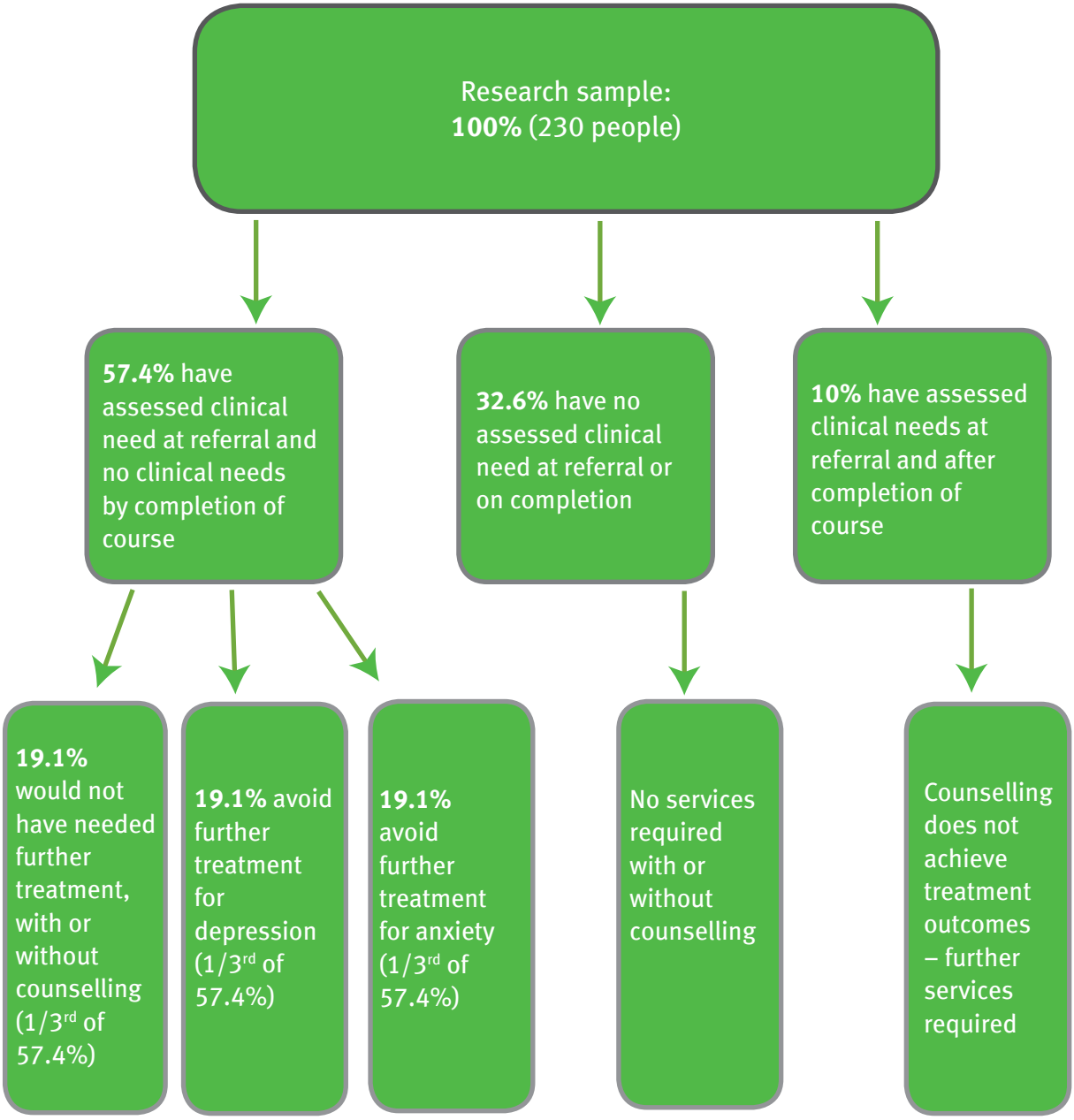

Table 2: Costs and savings in mental health care

Scenario	Incidence	Gross saving	Gross Cost of Counselling	Net Saving
No health care treatment required with or without counselling	32.60%	£0	£1,031,967	-£1,031,967
Health care still required after counselling	10%	£0	£316,554	-£316,554
Recover irrespective of counselling	19.10%	£0	£604,618.84	-£604,618.84
Avoid treatment for depression	19.10%	£1,709,257	£604,618.84	£1,104,637.72
Avoid treatment for anxiety	19.10%	£4,375,365.26	£604,618.84	£3,770,746.42
Total	**100%**	**£6,084,622**	**£3,162,378**	**£2,922,244**

In the scenario above, by investing in counselling for all 4,822 women who experience loss each year, the Government would make a net saving of £2.9 million through the avoidance of treatment for anxiety or depression.

Physical health

For someone who has experienced the loss of a child, the fear of another loss can make subsequent pregnancies extremely stressful. This may lead to a greater need for reassurance that the pregnancy is progressing healthily which, in turn, may lead to increased use of health care. Within the health care system, we highlight two routine procedures that may increase in frequency when an expectant parent has heightened concerns for the health of their unborn baby. These are antenatal routine observations and antenatal standard routine ultrasound scans. The costs of these procedures are shown in Table 3.

Table 3: Cost per procedure, according to National Schedule of Reference Costs 2017/18 (NHS Improvement, 2019)

Procedure	Total number per year	Cost per unit	Average per live birth (2017)
Antenatal routine observation	115,469	£486	One in six people
Antenatal standard routine ultrasound scan	899,358	£113	1.32 per person

The survey of 253 people who had used Petals found that counselling helped reduce levels of stress for subsequent pregnancies. The specific question was: 'If you became pregnant during or after your Petals Counselling, did our counselling affect your stress and anxiety levels about you and your baby's health during pregnancy?'

- I felt significantly less stressed: 29.3%
- I felt a bit less stressed and anxious than I would have done: 21.9%
- No impact: 7.8%
- Not applicable to me: 40.6%
- Made me feel worse: 0.4%

Of those who felt significantly less stressed (29.3% of the total) we model a cost scenario where:

- All of the 29.3% had one fewer scan than they would have done without counselling.
- 14.7% of the total (half of the 29.3%) had one fewer routine observation than they would have done without counselling.

In addition, we assume that the person who became less confident as a result of counselling has either an extra scan or observation and add the cost of half a scan and half an observation (£599).

In this case, considering just the factor of increased pregnancy health care alone generates a net cost of £2.67m, but a gross saving of £491,500 in reductions in scans and observations (Table 4).

Table 4: Costs and savings in antenatal care

Scenario	Incidence	Gross saving	Gross cost of counselling	Net saving
No change in health care use	70.7%	£0	-£2,238,201	-£2,238,201
Increase in health care use	0.4%	-£11,416	-£12,513	-£23,929
Decrease in scans	29.3%	£159,652	-£927,571	-£767,920
Decrease in observation	14.7%	£343,322	£0*	£343,322
Total	**100%**	**£491,557**	**-£3,178,285**	**-£2,686,727**

*cost included in row above

Employment

Just over a third (35.5%) of 253 Petals beneficiaries sampled said that counselling had 'really helped me return to work'. A further 13% said it had slightly impacted on their employment decision for the better. For 33% the question was not applicable (e.g. the participant is a full-time parent) and 0% said it had discouraged them. These are healthy results.

The cost of absence from work is high. The Health and Safety Executive values the average cost to government of seven or more days' absence at £8,700 in benefit payments and health care per episode (Health and Safety Executive, 2018). Up to five days absence costs £380, reflecting benefit payments made in some cases. There are additional costs to businesses and to the employee which we exclude. These values are calculated for incidence of illnesses which are work related and used here as the most realistic comparison because of the method of calculation.

Taking the £8,700 figure, this is the equivalent cost of just over 24 complete courses of counselling from Petals (144 individual sessions). If a course of counselling helps one person in every 24 (or just 4%) to avoid absence from work of seven or more days, the Government will break even by investing in this service.

Based on a scenario in which Petals plays a significant role in the decision to return to work of 35.5% of people using the service, we calculate what would happen where:

- One third of the 35.5% avoided a short absence from work as a result of the counselling;
- One third of the 35.5% avoided a longer absence;
- One third of the 35.5% would have returned for work on time with or without counselling;
- The rest of the total sample (64.5%) has no net effect.

The results of this can be seen in figure 2 and table 5.

Figure 2: Work trajectories among people using Petals' services

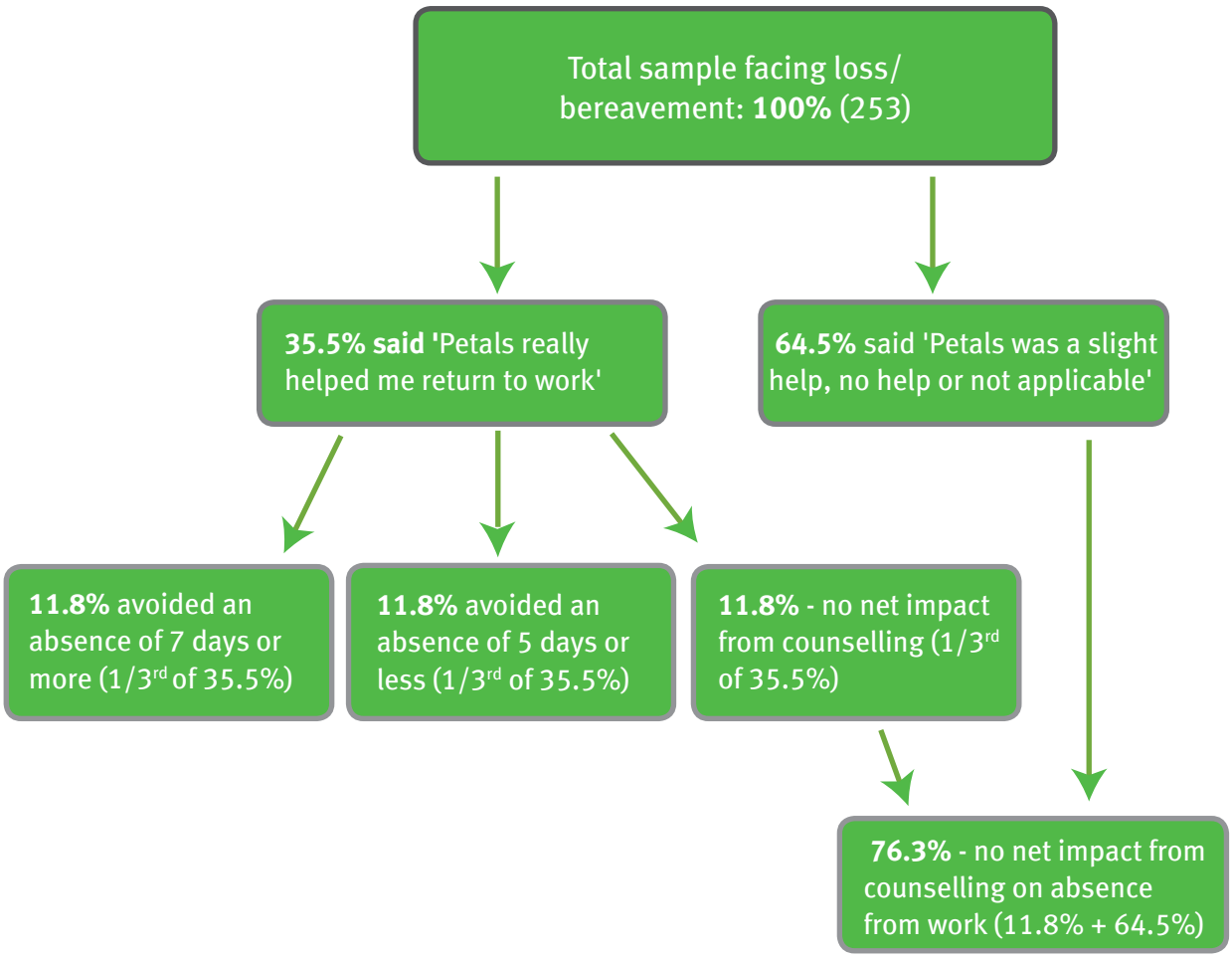

Table 5: Costs of benefits and sickness absence

Scenario	% of the total sample	Gross saving to Govt	Cost of provision	Net saving (rounded figures)
Avoided absence of 5 days or less	11.83%	£216,814	£374,589	-£157,776
Avoided absence of 7 days or more	11.83%	£4,963,891	£374,589	£4,589,302
No net impact	76.33%	£0	£2,416,365	-£2,416,365
Total	**100%**	**£5,180,705**	**£3,165,544**	**£2,015,161**

Taking a more conservative estimate – that is, assuming that a third of the people who said that counselling really helped them return to work still experienced no impact on employment from the counselling – the net saving to the Government would be £71,600 per 100 women suffering loss. The provision of counselling for all 4,822 women/couples experiencing loss would create a net gain (savings less the cost of provision) of just over £2 million per year. Where people are able to avoid repeated absences, the net savings increase further.

The composite calculation and case for investment

In the previous section, scenarios were modelled for health care and employment. Each was calculated in isolation – that is, assuming that everything else is irrelevant except the one factor we are concerned with at the time, be it mental health, physical health or employment.

Two of the three scenarios demonstrated a net gain for the Government. One scenario (physical health) predicted a net loss.

This section takes the cost for a national counselling service for 4,822 people/couples (£3.17m) and measures it against the gross gains in each area of examination. The reasoning here is that the Government only pays for the service once, but the benefits accrue in multiple areas at the same time. The estimates are shown in Table 6.

The net saving of a national counselling scheme based on the Petals model of six sessions plus a further six sessions for those requesting it when they have a subsequent pregnancy is £8.59m per year. These are direct savings to Government in addition to the health benefits to individuals and the potential wider benefits for families and society as a whole.

The case for investment is clear. A national support service would cost just £3.17 million per year and would be expected to achieve an average saving of £2.71 net for each pound invested.

Table 6: Composite calculation

Benefits	
Mental health (women)	£6,084,622
Physical health (women)	£491,557
Employment (women)	£5,180,705
Total	£11,756,884
Costs	
National cost of provision	£3,165,772
Net saving	**£8,591,113**

Conclusion

The NHS enables the nation to share the risks and costs of illness through collective tax and national insurance contributions. This is a sensible way to ensure that rich and poor can both have access to care when the worst happens. Despite this important promise, for parents who experience the tragedy of losing a baby, there is not an NHS national scheme that steps in to offer support with the grief and trauma that result.

The costs of providing a nationwide service are approximately £3.17 million per year.

The benefits to government – quantitative benefits from direct savings in health care and benefit expenditure – are large, even when conservative assumptions are used.

A net saving of £8.91 million from spending £3.17 million provides a financial incentive to act now.

Currently, Petals relies on the fundraising efforts of bereaved parents to maintain its services, adding to a patchwork of income from small grants and NHS contracts. The result is that whether a person receives support or not is dependent on where they live and which hospital they are treated at. And if they are offered Petals counselling, another bereaved parent will have fundraised some of the costs of provision. This is not an effective, efficient or equitable response to the national problem of baby loss.

The conclusion of this evaluation is that expanding the service to all who suffer this rare but most tragic event would be a good thing for society, a great thing for those directly affected and a prudent investment for government. Examples of effective care that are inexpensive and achieve large cost savings are unusual and should be an investment priority. The case for a national funding programme is extremely strong.

Appendix: Additional factors

Loss and trauma impact on many aspects of life, including relationships, health, families and marriages. Throughout this report, we have been cautious to base the investment case for counselling on quantitative evidence that directly relates to government. However, there are other areas where Petals can demonstrate a positive impact and this appendix summarises two; relationships and trauma. These calculations are not included in the main report, but are listed here to provide further detail to those interested in these topics.

Relationships

One of the most positive findings of the survey of 253 Petals clients was the impact on relationships. When asked about the impact of counselling on their relationship, 53% said it had had a significant positive impact, with a further 29% saying it had a slight (positive) effect.

The cost of relationship breakdown is large. The Relationship Foundation's 'Cost of Family Failure Index' estimated costs to Government of £47.5bn in benefits, housing, health and education where families break down and result in single-parent households.

We do not have the data to substantiate the incidence of benefit receipt resulting from relationship breakdown following loss and trauma at birth. In practice, separation is different for every couple and many of the costs are borne personally: people sell property; they pay alimony; they rent two houses. As an indication, the most recent DWP statistics on benefits show Housing Benefit payments average £95.42 per week, or £4,975 per year. The average Income Support payment in the UK is £71.11 per week, £3,708 per year. In simple terms, avoiding a relationship breakdown that leads to someone claiming these benefits would pay for 144 counselling sessions.

Valuations of trauma made by the Courts

Judicial College, 'Guidelines for the Assessment of General Damages in Personal Injury Cases' assess awards for damages and, in 'cases where there is a recognisable psychiatric injury', provide a valuation of the damage sustained by the claimant.

Where the psychiatric injury arises out of the death of a close relative, e.g. a child, spouse or parent, awards will tend to fall into (A)(c) or (B)(c) (see table overleaf) unless the long-term prognosis is especially poor - then an award within (A)(b) or (B)(b) may be appropriate (p11).

The guidance essentially monetises, as far as one can, the impact of the trauma that has been experienced. The awards consider factors including:

i. The injured person's ability to cope with life, education and work;

ii. The effect on the injured person's relationships with family, friends and those with whom he or she comes into contact;

iii. The extent to which treatment would be successful;

iv. Future vulnerability;

v. Prognosis.

This translates into award guidelines of:

Category	Sub-Category	Range of Award	Majority Award
A) Psychiatric Damage Generally	b) Moderately Severe	£15,200 to £43,710	Approx £29,000
	c) Moderate	£4,670 to £15,200	Approx £10,000
B) Post-Traumatic Stress Disorder	b) Moderately Severe	£18,450 to £47,720	Approx £26,500
	c) Moderate	£6,520 to £18,450	Approx £12,000

With moderately severe sub-categories, the damages award reflects long-term impact on the ability to work. The difference between moderately severe and moderate is approximately £19,000 for psychiatric damage, and £14,500 for post-traumatic stress disorder. As an illustrative calculation:

- If counselling were able to improve the mental health of a client from an assessment of moderately severe to moderate, the value of doing this (as measured above) would be £19,000 per person;
- If this were achieved for 167 mothers, the savings would equate to the provision of a national counselling service for those experiencing loss;
- 167 mothers are just 3.5% of the total women who experience loss each year.

Again, these are tentative and indicative figures designed to illustrate where additional savings could accrue. Whilst they are not contained in the composite savings calculations, they are intended to show the wider impact of trauma-informed counselling in areas more difficult to cost, such as emotional distress and relationship breakdown.

References

Bakhbakhi, D., Burden, C., Storey, C. and Siassakos, D. (2017) Care following stillbirth in high-resource settings: Latest evidence, guidelines, and best practice points. *Seminars in Fetal and Neonatal Medicine* (Vol. 22, No. 3, pp. 161-166). WB Saunders.

Bauer A. *et al.* (2014) *The costs of perinatal mental health problems.* London: Centre for Mental Health

Campbell, H.E., Kurinczuk, J.J., Heazell, A.E.P., Leal, J. and Rivero-Arias, O. (2018) Healthcare and wider societal implications of stillbirth: a population-based cost-of-illness study. *BJOG: An International Journal of Obstetrics & Gynaecology*, **125**(2), pp.108-117.

Dennis, C.L., Falah-Hassani, K. and Shiri, R., (2017) Prevalence of antenatal and postnatal anxiety: systematic review and meta-analysis. *The British Journal of Psychiatry*, **210**(5), pp.315-323.

Donaldson R. (2019) *Evaluation of the National Care Bereavement Pathway, Wave 2*. FivewaysNP [Online] Available from: https://nbcpathway.org.uk/sites/default/files/2019-05/NBCP%20wave%20two%20evaluation%20report%207%20May%202019_0.pdf [Accessed 27 September 2019]

Fockler, M.E., Ladhani, N.N.N., Watson, J. and Barrett, J.F. (2017) Pregnancy subsequent to stillbirth: medical and psychosocial aspects of care. *Seminars in Fetal and Neonatal Medicine* vol. 22, no. 3, pp. 186-192

Gamble, J., Creedy, D., Moyle, W., Webster, J., McAllister, M. and Dickson, P. (2005) Effectiveness of a counseling intervention after a traumatic childbirth: a randomized controlled trial. *Birth*, **32**(1), pp.11-19.

Gold, K.J., Leon, I., Boggs, M.E. and Sen, A. (2016) Depression and posttraumatic stress symptoms after perinatal loss in a population-based sample. *Journal of women's health*, **25**(3), pp.263-269.

Health and Safety Executive (2018) *Appraisal values or 'unit costs'* [Online] Available from: http://www.hse.gov.uk/economics/eauappraisal.htm [Accessed 27 September 2019]

Heazell, A.E., Siassakos, D., Blencowe, H., Burden, C., Bhutta, Z.A., Cacciatore, J., Dang, N., Das, J., Flenady, V., Gold, K.J. and Mensah, O.K. (2016) Stillbirths: economic and psychosocial consequences. *The Lancet*, **387**(10018), pp.604-616.

Heazell, A.E., Wojcieszek, A., Graham, N. and Stephens, L. (2019) Care in pregnancies after stillbirth and perinatal death. *International Journal of Birth and Parent Education*, **6**(2), pp.23-28.

Judicial College (2017) *Guidelines for the Assessment of General Damages in Personal Injury Cases* (14th Edition) (pp.11-15) Oxford: Oxford University Press

Ladhani, N.N.N., Fockler, M.E., Stephens, L., Barrett, J.F. and Heazell, A.E. (2018) No. 369 - Management of Pregnancy Subsequent to Stillbirth. *Journal of Obstetrics and Gynaecology Canada*, **40**(12), pp.1669-1683.

Lamont, K., Scott, N.W., Jones, G.T. and Bhattacharya, S. (2015) Risk of recurrent stillbirth: systematic review and meta-analysis. *British Medical Journal*, 350, p.h3080.

Malacova, E., Regan, A., Nassar, N., Raynes-Greenow, C., Leonard, H., Srinivasjois, R., Shand, A.W., Lavin, T. and Pereira, G. (2018) Risk of stillbirth, preterm delivery, and fetal growth restriction following exposure in a previous birth: systematic review and meta-analysis. *BJOG: An International Journal of Obstetrics & Gynaecology*, **125**(2), pp.183-192.

Mills, T.A., Ricklesford, C., Heazell, A.E.P., Cooke, A. and Lavender, T. (2016) Marvellous to mediocre: findings of national survey of UK practice and provision of care in pregnancies after stillbirth or neonatal death. *BMC pregnancy and childbirth*, **16**(1), p.101.

National Maternity Review (2016) *Better births: Improving outcomes of maternity services in England.* NHS England [Online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf [Accessed 4 June 2019].

NHS England, n.d.. *Perinatal*. [online] NHS England [Online] Available at: https://www.england.nhs.uk/mental-health/perinatal/ [Accessed 1 June, 2019]

NHS England (2016) *The five year forward view for mental health.* NHS England [Online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf [Accessed 1 June, 2019].

NHS Improvement (2019) *National Schedule of Reference Costs, 2017/18* [Online] Available at: https://improvement.nhs.uk/resources/reference-costs/ [Accessed 24 September 2019]

Office for National Statistics (ONS) (2019) *Deaths registered in England and Wales: 2017* [Online] Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2017#toc [Accessed 1 October]

Ogwulu, C.B., Jackson, L.J., Heazell, A.E. and Roberts, T.E. (2015) Exploring the intangible economic costs of stillbirth. *BMC pregnancy and childbirth*, **15**(1), p.188.

RCOG (2010) *Late interuterine fetal death and stillbirth: Green-top guideline no. 55.* Royal College of Obstetricians and Gynaecologists [Online] Available at: https://www.rcog.org.uk/globalassets/documents/guidelines/gtg_55.pdf [Accessed 4 June, 2019).

Redshaw, M., Rowe, R. and Henderson, J. (2014) *Listening to parents after stillbirth or the death of their baby after birth.* National Perinatal Epidemiology Unit [Online] Available at: https://www.npeu.ox.ac.uk/downloads/files/listeningtoparents/report/Listening%20to%20Parents%20Report%20-%20March%202014%20-%20FINAL%20-%20PROTECTED.pdf [Accessed 4 June, 2019].

Siassakos, D., Jackson, S., Gleeson, K., Chebsey, C., Ellis, A. and Storey, C. (2017) All bereaved parents are entitled to good care after stillbirth: a mixed-methods multicentre study (INSIGHT). *BJOG: An International Journal of Obstetrics & Gynaecology*, **125**(2), pp.160-170.

Wojcieszek, A.M., Boyle, F.M., Belizán, J.M., Cassidy, J., Cassidy, P., Erwich, J.J.H.M., Farrales, L., Gross, M.M., Heazell, A.E.P., Leisher, S.H. and Mills, T. (2016) Care in subsequent pregnancies following stillbirth: an international survey of parents. *BJOG: An International Journal of Obstetrics & Gynaecology*, **125**(2), pp.193-201.

Woody, C.A., Ferrari, A.J., Siskind, D.J., Whiteford, H.A. and Harris, M.G. (2017) A systematic review and meta-regression of the prevalence and incidence of perinatal depression. *Journal of Affective Disorders*, 219, pp.86-92.

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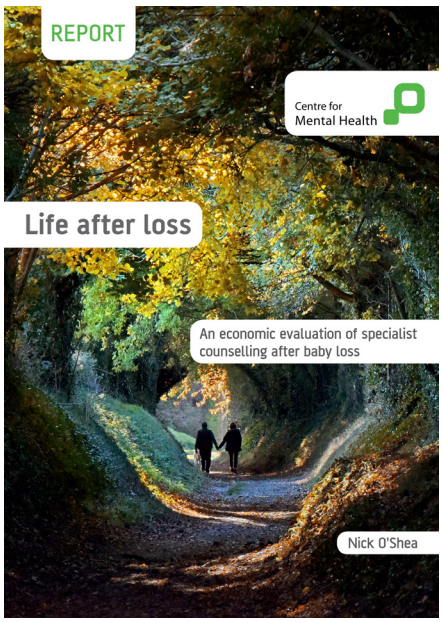

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Office 2D21, South Bank Technopark,

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