Survivors against terror

An independent review by Survivors Against Terror (SAT) on ways to improve the mental health response following major terrorist incidents:

The case for guaranteed mental health provision in the short, medium, and long term and the establishment of Regional Hubs

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Survivors Against Terror (SAT) was set up by people injured or bereaved by terrorism to tackle terrorism and the harm that is causes. Our objectives are three-fold:

1. Pushing for better support for survivors.
2. Changing policy to make future attacks less likely.
3. Helping the public play an active role in fighting terrorism.

In this paper we make specific, evidenced recommendations for improved mental health support for survivors of terror attacks as part of the national response to terrorism. It is important to highlight that survivors includes not only those were present and survived injuries, but also all those who were present both before and after the event and were witnesses, as well as the families and friends of all those affected.

Mental health support is of course part of a wider set of support policies that survivors of terror attacks should be guaranteed. SAT is currently researching a comparative report on the rights of survivors across a range of countries and in due course will publish our recommendations on a new 'Survivors' Charter'. The Government has promised to consult on such a charter and this paper is designed to inform the section covering mental health contained within it.

Why a robust approach to supporting survivors will help us fight terrorism

Terrorists indiscriminately target innocent members of the public, but the physical manifestation of the attack is a small part of the terrorists' overall strategy. First and foremost, terror attacks are attacks on our nation's mental health. Terrorists, lacking infrastructure to take on the state directly, use a form of psychological warfare which erodes our sense of safety and security. Attacks are designed to spread fear, anxiety, and division. By making us fearful they aim to change our way of life, in a way that their limited offensive capacity never could.

All states have a duty to protect and look after their citizens. That responsibility is heightened when harm is done to citizens as a proxy for harming the state. But even more fundamentally, if we are to defeat terrorism, we must take its attempts to undermine our collective mental health as being a front line in that battle. This of course requires public reassurance and mass communication approaches, but at a more granular level it also requires looking after the mental health of those most directly affected by the attack. And at present the state is failing in that duty.

The case for specialist services

Being a victim of terrorism is different from experiencing other violent trauma. This is due the indiscriminate nature of the victimisation, which is designed to erode a sense of safety, and provoke fear and shock at both an individual and community level (Hoffman, 2006; Hamblenet et al, 2012; Rubaltelliet et el, 2018).

Survivors of terror attacks experience a complex interplay between a profound personal trauma and the wider public and political aspects of an attack (Seeley, 2014; Lynch and Argomaniz, 2017). Particularly, extensive media coverage and public interest in the aftermath can be very overwhelming for survivors. Studies have shown that terrorist attacks can cause a shift in the survivor's identity, challenging their world views and creating feelings of disillusionment and angst (Benson et al, 2016).

The evidence for improved mental health support for terror survivors

In 2018, SAT, in partnership with Kantar, commissioned a survey of survivors of terror attacks. 271 people responded. Whilst the support of the emergency services, paramedics and police were rated highly, a shocking 76% rated mental health services as requiring improvement with a significant majority rating this as highly needs improving. The stories underlying this feedback are concerning.

Case Study 1: Ruth Murell (Manchester Survivor)

Ruth was in the foyer of the Manchester Arena with her 13yr old daughter and friends when the bomb exploded, her friend was killed, Ruth and her daughter were seriously injured, her friend's daughter escaped physical harm but witnessed the death of her mother.

Ruth and her daughter were hospitalised for a six-week period undergoing treatment for shrapnel wounds. They continued to undergo surgery for a further three years.

Ruth feels the care they have received for their physical wounds was first class however, following discharge from hospital, she found there was no psychological provision and was left in an appalling state of psychological distress.

> ***"…suffering flashbacks, bereavement, and lack of sleep. Most days, the anxiety was so overwhelming that we were unable to leave our home."***

Her GP prescribed a range of medication to help her to function. However, she was advised that the waiting list for the trauma counselling could be over 12 months.

She was offered some intermediate counselling by two agencies, neither were equipped to deal with Post Traumatic Stress Disorder (PTSD) or offered Trauma based therapy. She was recommended EMDR (Eye Movement De-sensitisation and Reprocessing- a PTSD treatment that is recommended by NICE), however, the NHS waiting list was12 months.

Ruth finally requested a list of approved Private Trauma/ EMDR Psychologists in her area and paid for her own weekly treatment for 18 months at £85.00 per hour.

"I feel incredibly lucky to have received an award from the Manchester Fund money to pay for my therapy. Without it, I don't think I would be here today."

In the absence of statutory services Ruth was dependent on charity to access appropriate care. There were many more survivors there that evening who did not qualify for the We Love Manchester fund and so had no option but to join the long waiting lists.

"Mental health services are diabolical here; I still have not seen a psychologist 14 months after the event" (Manchester Arena survivor)

What we can draw from previous learning

Repeated research has shown that early mental health support as well as access to specialist assessment and treatment has failed to gain the recognition and resources that other areas of the response to a terror attack have (Allsopp K, 2019).

As far back as 2003 the Legacy Study, which looked at the needs of survivors of the Northern Ireland 'troubles,' reported that the needs of victims came low down in the pecking order with the prime focus on the incident. It called for an Interdepartmental group to coordinate a national response for survivors and to develop services based on models of best practice to address their needs (Dover J, 2003).

Reviews of the 2005 bombings in London found that access to specialist services was inconsistent, financial contracts acted as barriers, there was a lack of central planning, and there was widespread failure to share data (Brewin C, 2009).

12 years on from that, after the Manchester Arena bombing, a central Hub was set up to give remote support and refer clients to their local services for psychological therapies. We met with those involved with the Hub who told us their own review has concluded that there is still a need to update policy and importantly that we have still not learned from the lessons of 2005.

Existing NHS models of access to mental health support, IAPT (Improving Access to Psychological Therapies), are not adequate as they are short term, do not include follow up and are too narrow in focus. They are also not equipped to deal with traumatic loss.

In order to be effective, they need to offer more than the current 10-session model, they need to be more proactive e.g. communicating with other agencies, school, employer etc and there needs to be more proactive outreach towards survivors. There is an urgent need for us to respond to the findings of previous research, so that when the next event occurs, we are not repeating the failings of yesterday.

What needs to be done

A subgroup of SAT has met with a range of organisations and expert individuals over a period of several months and identified and agreed on the following key areas: -

- The need for a centralised register of UK resident survivors of domestic and overseas terror attacks; this will enable proactive screening and follow up
- Survivors of terror attacks should be guaranteed a maximum wait for triage of three weeks following the attack and guaranteed access to follow up services by six weeks after that if appropriate
- To facilitate this access and ensure the guarantee is honoured there must be permanent regional hubs. These should be able to manage both acute events and the chronic psychological sequelae of major incidents
- Mental health provision must be available to children and families within the same services- we look to the Family Trauma Centre in Northern Ireland as an example of good practice.
- Government should invest in the research required to understand and learn more about the best treatment and therapies to help survivors
- Existing health care services need more training and education in the recognition and management of the health care issues after a major terrorist incident

Why we identified a central register of survivors of terror as a key component of mental health provision

"we were pretty much left to fall through gaps in the system of the NHS." (Manchester survivor)

Mental health symptoms often occur much later than the attack and survivors often delay presentation of their symptoms. Recommendation 1.1.18 of the NICE guidelines regarding the management of PTSD 2018 currently state that those responsible for coordinating the disaster plan should think about the routine use of a validated, brief screening instrument for PTSD at 1 month after the disaster. Therefore, an up-to-date register is fundamental to screening of the long-term needs of survivors. To this end it is imperative that there exists an appropriate way of registering survivors of terror attacks which is passed on through the necessary health care channels.

In order to achieve this goal, there needs to be: -

- Agreed systems of data sharing.
- An agreement on the coding to be used within healthcare systems and precisely who needs to be registered in the system.
- A clear plan within the Emergency, Preparedness, Resilience and Response (EPRR) policy to ensure that the processes to support mental wellbeing are frictionless and timely.
- Guidelines and clarification on data restriction laws so that relevant organisations can communicate swiftly.
- Clear lines of responsibility for ensuring that this happens.
- An agreement on who has access to this register.

Survivors may present themselves later and repeatedly to health services with unexplained physical symptoms related to PTSD. Therefore, good data recording and improved awareness of the significance of survivor status throughout the health care records will enable health care professionals to understand and signpost their patients to the appropriate services (NICE 2018).

Regional hubs to manage the psychological effects of major incidents in a timely way

"I was on the beach with my friend who was killed. I had to identify her at the mortuary that day. As I wasn't physically hurt, I felt as though I didn't matter. It took nearly a year before I got any help for PTSD" (Tunisia attack survivor)

Following the Tunisia Attacks in 2015, a psychological trauma outreach, screen and support service was set up to help survivors. This had some good results but unfortunately, took 10 months to be set up and was only funded to run for 12 months.

The Westminster Bridge attack in 2017 happened several days before the Tunisia service was officially closed and support had to be provided by existing mental health services in London because the complexities of commissioning and multiple Clinical Commissioning Groups across London made it difficult to set up a single service.

Manchester was able to set up a Hub following the Manchester Arena Bombing in 2017. They were able to set up early detection systems and attempted to streamline patients for the relevant psychological support. They have been able to support people in the short-term, but the long-term funding and plan is still unclear. They have told us a bid for further funding to research long term treatments and support was declined.

Permanent regional hubs should be set up, these can act as specialised major incident psychological support centres (able to surge in size depending on demand). These centres

should be able to set up acute phase responses to major incidents, but also should be involved in the long term follow up, screening, and support, as well as other activities such as training

and research. Regional hubs would liaise with the disaster planning teams, and the details of how to contact the service would be disseminated to all health care professionals so that there is no delay.

Guaranteed access

As part of the acute phase response, survivors should be guaranteed an initial assessment within 3 weeks by an appropriately trained triage mental health worker.
Those requiring support whether formal treatment or more structured support, should be guaranteed start to their care plan within 6 weeks of the assessment.

The Acute Phase Response

- Survivors should be offered an assessment of their mental health needs within 3 weeks of the event.
- Following assessment, a care plan or pathway should be identified as dictated by need.
- Where appropriate the individual or family should commence treatment or structured support within 6 weeks of this assessment.
- There should be a flexible care plan which accommodates the challenges that will be faced e.g., inquests, anniversaries, financial and legal hurdles, media management, co-ordination with workplaces/schools etc

The need to incorporate children and families into the management of the psychological effects

"It took 11 months after the attack and highlighting the lack of child mental health care on a TV programme to get help for my daughter"
(Manchester Arena survivor)

Much of the work to date has identified the needs of children and families as a separate issue. We have heard repeated stories of families having long waits to be seen through the existing regional Child and Adolescent Mental Health Services (CAMHS). There are no extra resources available to support this group and they are left in a postcode lottery having to wait on a long

waiting list of children and families who are waiting for non-terrorist related conditions. And even if they are seen the local services often lack the expertise and familiarity to deal with their needs.

Faced with this dilemma after the Manchester Arena Attack, one enterprising mother created the Manchester Survivors choir as a response to not getting the urgent support she needed for her son as well as hearing of many other such similar stories. The group continues to this day, and the friendships provided by it have proved a useful means of support.

Complex family dynamics can often occur when multiple survivors are living in one household. Research into the long-term effects on children and the resources to help them are notoriously limited. All of this leads to families in crisis, with many parents reluctant to access services until their children have been seen.

Furthermore, the effects can manifest years later so there needs to be a clear plan to screen and offer support beyond the initial phase. Schools and colleges need to be considered and how they might need support and training.

We lag behind other countries such as Northern Ireland which has set up the Family Trauma Centre (FTC). This is a regional Child and Adolescent Mental Health Service providing specialist treatment services for children, young people and their families following severe trauma.

There is an urgent need for fully funded family hubs which are resourced and trained to deal with the complex issues that children and families who are survivors of terror face.

More research is required to understand and learn more about the best treatment

Fortunately, terrorism remains a rare occurrence, and this brings with it a lack of evidence bases around the best ways to support the mental health needs of those involved. Whilst we are aware that NICE produced clear guidelines in 2018 on how to manage and treat Post Traumatic Stress Disorder, we feel further resources need to be committed to further research into the needs of survivors of terror attacks and what types of therapy make the most impact.

In order to be more prepared next time, we need

- Clear pathways of funding and research
- To actively work and collaborate with response teams internationally
- To evaluate the benefits of longer-term surveillance and screening
- To identify the fundamental issues which need research
- To understand better how to manage trauma and traumatic loss following incidents of this nature, where the stressor is sudden, violent or unexpected, and where there is a significant potential for longer term complications.
- Prospective long term (research) to establish the benefit of early mental health support following trauma and traumatic loss in the aftermath of a terrorist incident

The training and education of health and mental health care services in the recognition and management of survivors of major incidents

To make a difference we need to educate a wide range of people on the effects of health care issues following terrorist incidents. Mental health services as they are at the current time are unable to manage the additional demand of a mass casualty incident

- Therapists, counsellors and IAPT personnel need further training on the necessary treatments and skills to manage the psychological effects of trauma and loss on a significant scale and importantly, this should include child and group therapists.
- Members of the medical profession in contact with survivors need to understand the importance and significance of highlighting and recognising survivor status in the medical record and understand the benefit and significance of rapid intervention treatments.
- It is important that we use the correct terminology and describe survivors as survivors, rather than victims as this promotes their resilience.
- The general public need to understand the impact on survivors of terrorist incidents as well as understanding their own feelings and how to interact with survivors.
- Politicians and those in positions of authority need to understand the importance and significance of improving the mental health for survivors of terrorist incidents, as it is these people who are required to initiate the necessary changes.

Case Study 2 – Stuart Murray (Bereaved in Manchester Arena Bombing)

Stuart lost his 29-year-old stepson, Martyn, in the Manchester Arena Attack. Stuart is a practising doctor with over 25 years' experience as a general practitioner.

"…it frustrates me that some members of my family struggled early on to find a therapist who fully understood the impact of what had happened and the needs they had, and that in the beginning we had to pay privately as there were no NHS resources available. The ongoing intrusions of a trial and public inquiry 3 years later are impossible to escape, and the resultant impact of this on our mental health is poorly understood. Whilst we have received offers of support from many people along the way, there remains a lack of co-ordination between the different mental health and supportive agencies. More important there has been a lack of continuity for my family which ironically has been one of the fundamental aspects in my daily work as a GP over the course of my career.

I have observed the bonding between victim families not only within one incident, but between families of different incidents and yet there is no wider recognition of how to understand and develop this further. I have observed professional colleagues and other doctors struggle to understand and talk about what has happened to me. And I have met those involved with providing the mental health care that is required and heard them talk of the struggle to obtain funding for not only the treatment but also the ongoing research that is required"

The current situation

In 2020 the Home Office released £500,000 funding. This was given to four partner organisations; Cruse; Victim Support; The Foundation for Peace and The South London and Maudsley NHS Foundation Trust (SLAM) who are all committed to meeting the different support needs of survivors.

Hopefully, we will see a rapid improvement in the capacity to offer immediate practical and emotional support, based on a comprehensive assessment of survivors' needs, onward referral to outreach, screening, and (where indicated) assessment and referrals for psychological treatments, through these coordinated support services.

This shows a willingness by government to tackle the issues around access to services.

However, we want a commitment to ensure there is always funding there for specialist mental health services for terror survivors. We are calling for a statutory guarantee so it is not dependent on how much there is in the budget on a particular year or which party is in power. There should be funded capacity to respond to the immediate mental health needs of survivors following a terrorist attack and there should be funding to support all survivors' long term mental health needs.

We also feel there needs to be joined up working between the commissioned services and primary health care. Too many of our members have reported presenting at their doctor's and been given no clear route into the specialist services that are out there. There has to be provision for survivors regardless of where they are in the country, good mental health support should not be a matter of where one lives

It is worth noting that none of the services granted funding offer support to children and young people. SAT will look at this in a further piece of work to be completed in 2021.

Conclusion

We need to change the way we see terrorism and realise the assault it represents on our mental health. This is an issue that can affect the public, but survivors are on the front line and deserve much better support.

Progress has already been made through the Manchester Hub created in 2017. It is important that we learn from what has happened before and recognise that timely interventions, screening and treatment can affect the long-term outcomes of those caught up in terrorist incidents.

NICE 2018 provided good guidance on how to screen and manage PTSD and the importance of disaster planning. It is now time for the commissioners and providers of health care to make this work.

Crucially it is time to provide guarantees to survivors of terror attacks of a three-week maximum triage and a six-week maximum for appropriate service provision. These maximum waiting times should be guaranteed in the Survivors Charter to be published later this year.

It is not right that the mental health needs continue to be neglected despite the expanding literature which suggests we should be doing otherwise. Nor is this how the general public would want survivors to be treated.

"Finally receiving skilled professional treatment helped me make sense not just of what had happened to me but more importantly of how I responded to it. The psychologist enabled me to see that the symptoms I found so distressing were a normal response to severe trauma and taught me how to deal with and ultimately overcome them. She helped me move from surviving to thriving and I will be forever grateful for her help but sorry I had to wait 18 months to receive it."

About Survivors Against Terror

Survivors Against Terror is a network of family members who have lost a loved one to terror and survivors of terror attacks. Our mission is to help our country tackle terrorism more effectively and ensure victims and their families get the support they deserve.

http://www.survivorsagainstterror.org.uk/

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