



ROYAL BLIND



SCOTTISH WAR BLINDED
FOR ALL VETERANS WITH SIGHT LOSS



EMOTIONAL SUPPORT FOR SIGHT LOSS

RESEARCH FINDINGS

Research by Royal Blind and Scottish War Blinded with the Mental Health Foundation into the mental health impacts of visual impairment.



Mental Health
Foundation
Scotland

About Royal Blind and Scottish War Blinded

Royal Blind is Scotland's largest visual impairment organisation. We provide educational, care and transcription services for blind and partially sighted people of all ages. Our vision is to see a community in which blind and partially sighted people, including those who have other disabilities, are fully included and lead fulfilling lives.

We operate only in Scotland and care for, educate and employ blind and partially sighted people from across the country, with occasional referrals from the wider UK.

Our sister charity is Scottish War Blinded, which provides free support for all veterans with sight loss, no matter if they lost their sight during or after service.

Foreword

The issue of support for an increasing number of people with mental health needs in Scotland has risen to the top of the agenda for our health services. There is a growing awareness that support for our mental as well as our physical wellbeing is essential if we are going to be a healthier, happier society.

This development in health policy is one we welcome, because we believe there has to be a growing recognition of the impact sight loss can have on emotional wellbeing. A diagnosis of a sight loss condition is a life-changing event, and for people who are born with visual impairment there can be a range of emotional impacts as they face barriers and stigma which still exist in our society.

Last year, we published our policy report "Social Connections and Sight Loss." This report studied the links between loneliness and sight loss, and when we started our research we believed we would find strong evidence showing many visually impaired people have faced social isolation. This belief was borne out by our findings, suggesting that around two thirds of blind and partially sighted people have experienced loneliness because of their sight loss.

We consulted with nearly 300 people with visual impairment in researching "Social Connections and Sight Loss." The report highlighted many experiences of challenges to mental wellbeing and episodes of emotional trauma as a result of visual impairment. This ranged from blind and partially

sighted pupils struggling to make friendships, young people accessing counselling to help them manage anxiety linked to their visual impairment and veterans with sight loss experiencing chronic mental health challenges.

We wanted to build on these findings to develop a deeper understanding of the wider emotional impact of sight loss. We embarked on a new study to establish how often people with visual impairment who use our services had experienced mental health challenges. We also wanted to learn whether health services were seeking to identify when people with sight loss needed mental health support and whether they were being offered any specific support to deal with the emotional impact of visual impairment. This research is set out in this report which we believe helps make clear the need to improve support.

We have been very pleased to collaborate with the Mental Health Foundation in taking this study forward and developing policy recommendations. Given the wealth of experience in our organisations in both sight loss and mental health, we hope our policy proposals will be seriously considered and help drive improvements in support which are clearly required.



Mark O'Donnell
Chief Executive of Royal Blind and Scottish War Blinded

Foreword by Lee Knifton

Seventy years ago, our founder Derek Richter talked about the impact of issues like trauma, neglect and poverty on our mental health. Evidence over the last 30 years has shed more light on the causes of mental ill-health, illuminating how social, economic, family and emotional factors make us more or less likely to develop a mental health problem.



Together, these factors interact and influence each other. As we have understood how many of us experience mental health problems, the focus has been on finding and developing effective treatments. While this is vitally important, it's become clear that we can't treat our way out of the current mental health crisis. Prevention in all its forms must become a national priority.

We need to turn our priority to examine and address the societal causes that are leading to poor mental health. One of these priorities is to re-connect mental health and physical health and address the prevalence of mental ill-health among people with long-term physical conditions.

Since the founding of the NHS in 1948, physical care and mental health care have been deliberately disconnected. In recent years we've started to bridge those divides. Poor physical health can lead to an increased risk of developing mental health problems. Similarly, poor mental health can negatively impact on physical health.

That's why the Foundation developed a programme on the emotional needs of children and young people with long term physical conditions. We also undertook research into the emotional and psychological impact of people with cancer and are developing national programmes in areas including Diabetes and many other conditions.

Building on our body of work in this area, we're delighted to work with Royal Blind to understand and champion the mental health needs of people with sight loss. This report echoes the increasing calls for healthcare professionals to consider psychological wellbeing when treating physical conditions. All physical health problems have a psychological and emotional dimension that must be addressed upon diagnosis and throughout a support pathway. Nobody should be left to cope with emotional distress on their own.

Our joint research argues that holistic, integrated person-centred support that fully addresses the emotional and psychological needs of those living with sight loss will empower people to live healthier and fulfilling lives. This means offering the right support at the right time and giving people greater control over their emotional wellbeing.

It's clear that if we tackle the risk factors that damage our mental health, and promote the protective factors that enhance it, we can achieve this critical mission of reducing the level and severity of mental health problems. We can also improve resilience to difficult life events that aren't readily preventable.

Lee Knifton
Director of Scotland and Northern Ireland,
Mental Health Foundation

About Mental Health Foundation Scotland

With prevention at the heart of what we do, our aim is to find and address the sources of mental health problems so that everyone can thrive. Our vision is good mental health for all. Our mission is to help people understand, protect and sustain their mental health.

Good mental health is fundamental to living a happy and healthy life, but compared to physical health, so little is still known about mental-ill health and how to prevent it. That must change.

Scotland's unacceptably high level of mental ill-health is the public health challenge of our time. One in six adults and one in eight 5 to 19-year-olds meet the criteria for a common mental health problem every week. Suicide is the leading killer of men and women between the ages of 15-35. And fewer than one in eight adults say they are thriving.

Our programmes, research and campaigns impact people throughout Scotland and target some of the most vulnerable and high-risk groups in our society, including:

- Children with life limiting and long-term conditions
- People who have experienced neglect and abuse
- Children and young people
- Mums and babies
- Families who have been bereaved by suicide
- Refugees and asylum seekers

Our role is to advocate for the societal changes needed as well as to co-produce, test and apply new solutions for our mental health beyond the health sector: in our workplaces, schools, homes, and in our communities and neighbourhoods that experience the greatest disadvantage.



Mental Health
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The need to improve mental health services for people with sight loss.



Each year 1 in 4 of us will experience a mental health problem. However, mental illness is not equally distributed across the population. People living in the most deprived areas are four times more likely to report two symptoms of depression compared to those in the least deprived areas. Environmental factors such as poverty, adverse childhood experiences (ACEs), trauma, toxic relationships, social isolation and, too often, disability are key predictors of mental ill health.

Scotland's ten-year Mental Health Strategy was launched in 2017 with forty actions and we're pleased to see progress in some areas. However, there are still significant challenges. While stigma is starting to crumble more people are coming forward for help and support services are struggling to cope with demand.

Mental illness costs Scotland around £11 billion a year. In 2017 over one and a quarter million working days were lost due to self-reported work-related stress, depression or anxiety. The Mental Health Foundation works with employers to help them create mentally healthy working environments. Employment is also a key issue for working age people with visual impairment as two thirds of working-age people who are registered as blind and partially sighted in Scotland are not in paid employment, which can lead to financial problems, stress and isolation.

In recent years we've seen more children and young people struggling to cope. Since 2013/14 there's been a 22 per cent rise in the number of referrals to specialist services. The Mental Health Foundation's research has found that a range of societal pressures, including pressures to succeed, exam stress and body image are contributing to this increase. Visual impairment in young people can lead to challenges in isolation and confidence. The Scottish Government has pledged to roll out school-based counsellors but we believe all school children, including blind and partially

sighted pupils, should benefit from comprehensive mental health education to equip them with the tools to understand their emotions.

There have been a number of positive developments in mental health policy. The National Suicide Prevention Leadership Group has been established to provide strategic and national oversight of suicide prevention work across Scotland. Scotland's new national public health body – Public Health Scotland – has placed mental health as one of its six strategic priorities. The new process for applying for a Certificate of Visual Impairment will include information being made available on Breathing Space. We believe it is also vital that the Scottish Government's See Hear strategy promotes better signposting to mental health support for people accessing sensory impairment services, and that a new low vision services strategy recognises the need to support the emotional needs of people with sight loss.

If we are to succeed in nurturing a mentally healthier Scotland we must integrate mental health into all policies at national and local level, from housing and planning to giving every child the best possible start in life. We must also ensure people with visual impairment can access support for emotional well-being to help them live well with sight loss.

Methodology

The survey was conducted through questionnaires and interviews amongst both young and older people using Royal Blind and Scottish War Blinded's services. Where pupils and young adults were not able to respond themselves, parents were invited to respond to the questionnaire. This was also the case for the carers of some older service users, but the great majority were completed by people with sight loss themselves.

378 people took part in the research.

Key messages

The vast majority of respondents said they had experienced challenges to their mental health a result of their visual impairment.

- 320 people out of 378 respondents (85%) stated that sight loss had an impact on their emotional well-being. Only 15% indicated they had not experienced any mental health challenges.
 - Two thirds of respondents indicated they had not been put in touch with a service to support them with the emotional impact of their sight loss following their diagnosis.
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Summary of findings

The four top challenges to emotional wellbeing identified in the survey were worry about the future; feeling of anxiousness; being upset; and feeling angry.

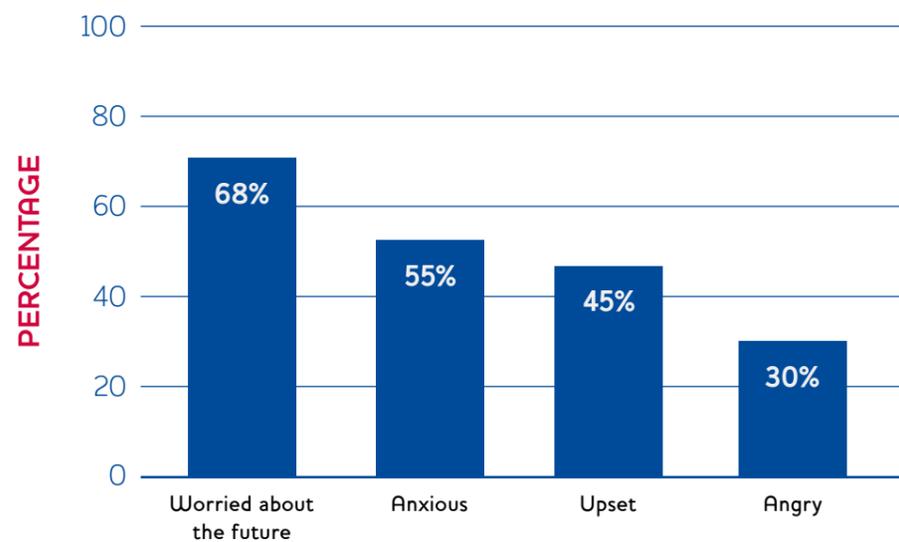
Those people who felt their sight loss had not resulted in any of these emotional responses indicated that they felt it was an inevitable consequence of ageing they had to accept and manage.

For the far greater number of people who felt their sight loss had resulted in one or more of these emotional responses, they indicated there were a number of causes. These included loss of confidence, diminished self-esteem and inability to undertake activities they had previously been able to engage in.

Results

Question 1:

Did your sight loss have an impact on your emotional wellbeing? (Tick all that apply)



Answer Choices	Frequency	Percentage
Worried about the future	218	68%
Anxious	177	55%
Upset	144	45%
Angry	96	30%

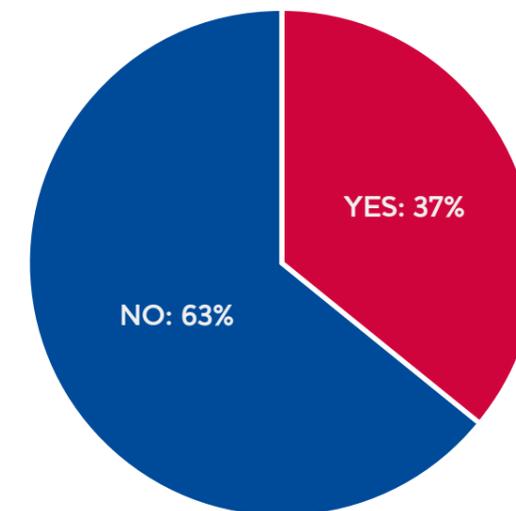
Answered: 320 Skipped: 58

Over 80% of respondents said that sight loss had an impact on their emotional well-being. Only 17% did not indicate they had experienced any mental health challenges.

Question 2:

Were you offered any support to help with the emotional impact of your sight loss?

We asked specifically if respondents had been offered support with the emotional impact of sight loss.



Answer Choices	Frequency	Percentage
Yes	122	37%
No	206	63%
Total	328	

Answered: 328 Skipped: 50

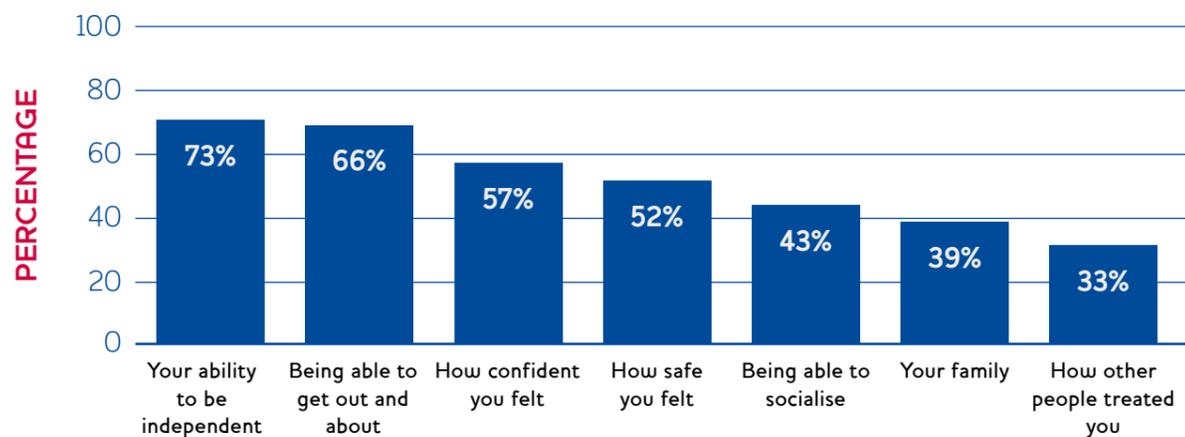
Almost two thirds of respondents indicated that they had not been offered support to help with the emotional impact of the visual impairment.

Results (CONTINUED)

Question 3:

Did your sight loss have an effect on the following? (Tick all that apply)

To understand some of the drivers of emotional wellbeing challenges for people with visual impairment, we asked if sight loss had an effect on various aspects of their life.



Answer Choices

Frequency Percentage

Your ability to be independent	258	73%
Being able to get out and about	236	66%
How confident you felt	201	57%
How safe you felt	183	52%
Being able to socialise	154	43%
Your family	138	39%
How other people treated you	118	33%

Answered: 355 Skipped: 23

The most frequently recorded effects were on people's ability to be independent, their mobility and their confidence.

Case study: Eddie McKay

Eddie McKay, 62, of Greenock, served with the Royal Engineers for four-and-a-half years and worked in various jobs after his service. He had been working as a bus driver for just over a decade when he was diagnosed with glaucoma in 2007.

No longer able to work, and feeling no one was supporting him, Eddie says over time his emotional wellbeing began to spiral.

"When they told me I have glaucoma I don't think it sank in" Eddie explained. "I didn't know what to do. All I wanted someone to say was it's going to be alright and this is what's going to happen. It's like a big cloud on you."

"You tend to bottle up how you're feeling. You get to the stage where you think, is it worth saying anything? You feel there's no help there. It's then that I started to think about personal things. What happens when it's dark? Around my house at night it's pitch black and no street lights, so how do I get out?"

"Your mind starts going, and you're thinking about your own safety. I'm sitting there thinking, I'm used to getting up and going to work. What am I going to do now? You can't take part in things and you feel a bit out of touch. You start to feel isolated."

Eddie was eventually diagnosed with depression. He said: "I started looking about for clubs and things, but there was nothing for me. I had no one else to talk about how I was feeling. I was feeling really, really angry. My mental health was going down and down throughout all of this. I was sent to a psychiatrist for my depression and I was put on anti-depressants. It was all the changes in my life. All of it just balls up into you. I'd just get angry with people. I'm still on the anti-depressants now."

Eddie joined Scottish War Blinded in 2010, and was one of the first veterans to start attending our Paisley activity hub, the Hawkhead Centre, when it opened in October 2017. Participating in everything from the centre's skills kitchen and IT sessions to various outings, he is now Chairman of the Hawkhead Members' Council.

"The Hawkhead Centre has changed my life for the better," he said. "It's a very important part of my life. Sight loss takes your confidence down – I think that's why I put myself down for the centre's Members' Council. It's night and day between how I feel now and how I'd felt before I started attending. I've not been as aggressive or angry."

"Scottish War Blinded listens to you. You can talk to anybody at Hawkhead. Members have all been in the services but we've all had different life experiences. You can listen to others and hear what they've experienced, and discover different ways to do things. Had I had that all those years ago when I was diagnosed, I probably wouldn't have had half of the hassle."



Case study: Kirin Saeed

Kirin Saeed, 50, is a Braille Proof Reader at the Scottish Braille Press which is run by Royal Blind. Kirin was born partially sighted, losing her sight entirely at the age of eleven. She went to Chorleywood College for blind and partially sighted girls. Kirin says she learned to cope with losing her sight as a child, but further deterioration in what little vision she had left as an adult affected her greatly.

Kirin had retained some light perception but lost this at the same time as her husband died. "This had a massive emotional impact for me. It started with a physical impact of losing my light perception. It meant that when I walked downstairs I felt like I was going to be tipped over. This made me anxious and affected my confidence, but people still expected me to be able to cope which put further stress on me."

Kirin has never been offered counselling to deal with the impact of her visual impairment. She sought bereavement counselling when she lost her husband, but this didn't address the effect of her further sight loss on her emotional wellbeing. "I felt like because I had further sight loss at the time of my bereavement, the counselling helped me with one part of what I was going through, but not the other."

Kirin believes there is not enough awareness of the impact of disability on mental health.



"Emotional wellbeing is not recognised enough in the disability community. Too often people think they just have to get on with it, and yet you have to fight battles at all levels so much of the time. You have to constantly argue for support, argue your case for equipment, argue your case for help with access to work. This is stressful in itself."

Kirin says lack of awareness of visual impairment in society can impact on emotional wellbeing too. "People are always asking me how I lost my sight and whether there will ever be a cure for it. I know they are well meaning but always being asked this has an impact too."

Kirin says being in employment has made a big and positive difference for her. "The biggest thing to help me get in a better place has been getting the job at the Scottish Braille Press. The opportunity to get employment, and the right kind of work. It gets me up, gets me active, I meet other people and at the end of the day I can go home and relax. The right workplace, offering you support makes a huge difference and really helps you confidence."

"Through work, I've been offered opportunities to be involved in other activities such as consumer rights and research. I have really enjoyed being involved and knowing that I am making a positive impact."

Focus group

In November 2019, Scottish War Blinded held a joint focus group on the emotional impact of sight loss with the Mental Health Foundation Scotland at the Hawkhead Centre in Paisley. Seven members of Scottish War Blinded discussed how sight loss had affected their emotional wellbeing, what had helped them to cope and what support they would find helpful in the future.

Issues arising in the focus group

Veterans talked about the experience of losing their sight and how this had affected their independence and mental health. Members of the group had experienced loneliness and isolation as a result of their sight loss, finding it harder to get out and about. Experiences of shopping and public transport had resulted in anxiety and frustration, as a lack of understanding of visual impairment had meant they were not offered the support they needed, and some people they encountered had even questioned whether they had a disability. Dealing with public sector services had also resulted in stressful situations, particularly in dealing with issues such as accessing benefits and a lack of practical support from health services. One participant had been particularly affected by his experience of bereavement after the death of his wife, and others felt that support at times of transitions was important.

None of the participants of the group had been offered or asked if they needed support for their emotional health after their diagnosis, nor were they signposted to any organisations who could help. They felt that services should be better linked up so that people with visual impairment could be referred to organisations that could help them deal with the emotional impact of sight loss. It was felt that peer support and speaking to people with experience and understanding of the impact of sight loss was of particular benefit, and that befriending schemes could be helpful too. In some circumstances participants thought that medical counselling services could help. All the

members of the focus group felt that being able to attend the Hawkhead Centre had made a huge difference to them.

"You're sitting in the house, your sight is getting less and less, you're on a right downer, you don't care if the roof falls in, you are looking for someone to talk to. A bit of therapy, someone who has identification with what you've got, so you can unload to them. Someone you can see on a regular basis who has got knowledge about sight loss."

"I was always one for doing things myself. I was in the building trades for years. It got to the stage that I had to ask my son to do things, even changing a plug because I couldn't see the screws. Small things build up to big things because I get uptight about it, I would think I should be able to do this. Because I've always done things myself before it gets to me mentally."

Causes of emotional challenges

Participants in the survey were asked about how sight loss had affected their mental wellbeing.

The emotional impact of sight loss

“Takes away confidence and is very isolating. More needs to be done on educating peers.”

“When very young my son had lots of friends and was always included in birthday parties but as he got older the other children became less interested as he did not have the same abilities or interests and therefore things like party invites dropped off but he could still hear the others in his class talking about going to each others’ parties or sleep overs which he found hard.”

“Suppose I felt sorry for myself and my life as I knew it had ended.”

“It happened sudden, I thought I was going mad, could not understand it.”

“I was very upset at first, took me a while to accept I had sight loss.”

“I lost all self-esteem and confidence.”

“My confidence was knocked for six.”

Problems accessing support

“Whilst in mainstream he was referred to Child and Adolescent Mental Health Services. It took more than a year from referral to the first appointment. Since going to his specialist school his support has been much better.”

“Diagnosed cortical blindness in 2012 and with no offer of support until last year via school, but nothing up to that point by agencies involved. I’ve sought independent counselling.”

The positive impact support can have

“They made me feel I wasn’t alone and there was a future.”

“Compassion and understanding of what was happening to me. After that support went from strength to strength.”

“Being able to talk to people who had vision problems longer than me. Feeling that other people know what I was going through. Able to hear their experiences and feel more positive about what the future can hold.”

“She came and talked to me. It made me feel so much better talking about what was happening to me and although my sight loss is gradual she gave me lots of advice to help as it gets worse.”

Our policy recommendations

How we believe support for emotional wellbeing can be improved for people with sight loss.

01.

Increase awareness of the mental health needs of people with sight loss in primary care settings, including in low vision services. This includes training for staff to understand the emotional impact of sight loss at point of diagnosis.

02.

GPs and opticians should regularly screen for depression among people experiencing sight loss and signpost to support.

03.

Provide opticians and optometrists with training and resources which empower them to provide sight loss counselling and emotional support.

04.

Ensure clear pathways for psychological support upon diagnosis. Patient choice and a range of treatment options are key – including Cognitive Behavioural Therapies, counselling, social prescribing and psychological therapies.

05.

Ensure tailored, person-centred social care and support plans that address mental health risks and triggers, such as mobility, access to services, employment, economic support and other needs.

06.

Ensure people with sight loss and their families know where to go for help during crisis periods related to their sight loss. Advice and information should always be provided in accessible formats.

References and thanks

Scottish Government Mental Health Strategy 2017–2027:

<https://www.gov.scot/publications/mental-health-strategy-2017-2027/>

Statistics on Vision Impairment are from the Scottish Vision Strategy 2013–18:

https://www.rnib.org.uk/sites/default/files/Scot_Vision_Strategy_refresh.pdf

Royal Blind and Scottish War Blinded would like to express our sincere thanks to everyone who took the time to take part in our survey and share their views with us on this important issue for people living with sight loss. In particular we would like to thank Mental Health Foundation Scotland for providing their insight and expertise into mental health research, policy and services.

Royal Blind and Scottish War Blinded Policy and Research

Royal Blind and Scottish War Blinded engage in policy development and research to take forward our vision to see a community in which blind and partially sighted people, including those who have other disabilities, are fully included and lead fulfilling lives. We believe it is vital that every level of government is aware of the needs and experiences of people affected by visual impairment when they make key decisions on issues like reform of public services or the future of healthcare.

Our recent reports include “Our Vision For Equal Education” on specialist support for pupils with vision impairment, and “Social Connections and Sight Loss” on the links between sight loss and loneliness. You can find out more about our policy and research at www.royalblind.org/campaigns.

Mental Health Foundation Scotland takes forward policy development which focusses on social justice and inequality in mental health, raising awareness of mental health with the public and working in partnership with community organisations, policy makers and researchers.

You can find out more about the research and policy engagement of Mental Health Foundation Scotland at mentalhealth.org.uk/scotland.





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