



Jessie May
Children's Hospice at Home

Our Impact

2023-2024



Welcome



Daniel Cheesman
CEO

What a year it has been! Having launched the five year strategy two years ago the wheels are most definitely in motion in terms of implementing changes to achieve our strategic objectives. Right at the heart of the strategy is our commitment to support more children, young people and their families and it is encouraging to see us making strides in this area in the last twelve months as this report shows.

A highlight for me in the last year has been welcoming Philippa Brownjohn as our Honorary President. Philippa is the mum of Jessie May and 2024 marks what would have been Jessie's 30th birthday so it feels very timely to have her involved in the charity again.

It is an honour to be leading this very special charity and I would like to thank everyone who is involved and in whatever way – you all make Jessie May the charity that it is.

On behalf of the Board of Trustees, I would like to thank our supporters, partners and funders for everything you do. Without everyone who supports Jessie May, we would not be able to do what we do in providing vital support, at home, to our Jessie May children, young people and their families.

I also want to thank our fantastic Jessie May team for their commitment, support and dedication – they simply are the best. The final thank you is to our children, young people and families, for inviting us into their homes. We hope that you enjoy reading this report.



Tiggy McCool
Chair of Trustees

About us

**Started by a family, for families,
and now shaped by families.**

An at-home hospice that provides support for children and their families across Bristol, South Gloucestershire, North Somerset, Bath & North East Somerset, and Swindon & Wiltshire.

Home is that place where children feel most loved, where they are safe and thrive, and where they are most comfortable, surrounded by their family, friends, pets and toys.

Because there really is

No place like home

Our vision...

is that **all** children and young people with life limiting and life threatening conditions are supported to have the very best quality of life possible, and have the choice to live and die in their own homes, with their families.

Our mission...

at Jessie May is to provide the very best care and support possible, at home, for children and young people with life-limiting and life-threatening conditions, and for their whole families.

In life, at the end of life, and in bereavement.

Our values...

**We put
children &
families first**

**We are kind,
passionate &
committed**

**We are honest,
respectful &
collaborative**

No place like home – an update on our five year strategy

We are now approaching the half way mark of our five year strategy, and we've focused on six priority areas:

Strategy highlights in the last 12 months include:

1

24/7 end-of-life support at home – We have been part of a collaboration of palliative care providers in Bristol, North Somerset and South Gloucestershire running a pilot to develop a service to support end-of life-care at home. All partners are now committed to working towards this becoming a sustainable model and offering choice to families.

2

New children and family projects – We have invested in family engagement and have grown and developed the family events programme, providing families with the opportunity to meet other families and to meet Jessie May nurses outside their care visits.

3

Children and family involvement – We have listened to children and families and have increased the hours of direct support provided from 4,377 hours to 4,656 hours in the year. We have a target in the next 12 months of increasing this by a further 20% to 5,590 hours.

4

Influencing – We have worked in partnership with Together For Short Lives and the wider children's hospice sector to highlight the challenges facing children's palliative care funding.

5

Sustainable fundraising – We have continued to fundraise effectively and grown our supporter base. We've introduced a new finance system, Xledger, that will support our growth as a charity.

6

People – We have continued to ensure that our nurses are trained to the highest standards of children's palliative care.

External evaluation findings

Over the last 12 months Jessie May has been working with health and social care evaluators Apteligen, to evaluate the impact of Jessie May, both in terms of our outcomes with families and our economic impact on the local health system.

Over the next few months we will be sharing the headlines from this evaluation as it has clearly highlighted the huge impact that Jessie May has on the families that we work with, breaking our offer down into three main stages:

Specialist respite care for children and families

End of life care and support

Bereavement support

Benefits of support across all three of these stages for children and families:

- Developing trusting relationships with individual Jessie May staff.

- Feeling understood, valued and supported by Jessie May nurses.

- Feeling part of a wider community of professionals and families.

Benefits of support across all three of these stages for other professionals and the wider system:

- Having greater knowledge of the child's clinical condition and the family's circumstances

- Delivery of holistic and personalised care

- Experiencing reduced demand, now and in the future

Nurse Q&A



“A typical visit with Hope, where she enjoys being read to and rolling around on the floor. A genuine moment of connection between us”

- Mary Hunt answers some questions about her life as a nurse working at Jessie May

Q: How long have you been with Jessie May?

A: Since 2016, when we started the Swindon and Wiltshire service that January. I was one of the original nurses.

Q: What were you doing before? What brought you to the role?

A: I worked for 20 years on the children’s ward in Swindon Hospital. I looked after Hope on the ward as well, so I had a lot of experience with paediatric care.

Q: What attracted you to Jessie May?

A: I really wanted to do hospice at home. I saw Andy’s [another Jessie May nurse] video on Children in Need, and it looked like a rewarding job. The personal touch of getting to know families properly was appealing to me.

Q: How does Jessie May differ from other support services in the care sector?

A: At Jessie May, we have the opportunity to build personal relationships with families, unlike the more transactional approach you

will find in a hospital setting. We get to know the family and their challenges, which helps us provide better care.

Q: Let’s talk about Hope [pictured] and your relationship with her. How has that changed over the years?

A: Well, we’ve got to know Hope’s family really well since Jessie May was launched in Swindon. We’ve watched Hope and her siblings grow up, and have been there for some major life events. It’s been lovely to be a part of their journey.

Q: Could you tell us a bit more about Hope’s condition and your interactions with her?

A: Hope is nonverbal, but she uses communication programmes, and we try our best to understand her needs and preferences. Despite the challenges, we’ve built a routine and a relationship based on trust and understanding.

Q: How do you manage the varying complex needs of families like Hope’s?

A: Each family is unique, and it’s essential to adapt to their specific needs. We rely on our skills and experience to provide the best care possible, but ongoing support and funding are crucial to our work.

Q: Can you share the story behind a memorable photo of you and Hope?

A: The photo (opposite) captures a typical visit with Hope, where she enjoys being read to and rolling around on the floor. It wasn’t staged; it’s just a genuine moment of connection between us.

Q: How do families feel about having photos taken during visits?

A: It’s not always easy to ask, but for families like Hope’s, having these memories documented is meaningful. It’s a way to share their journey and raise awareness about the important work of organisations like Jessie May.

Q: How do you cope with the tough days working in palliative care?

A: We support each other as a team. While the tough days are there, they are outweighed by the positive ones. Knowing that we’re making a difference, even in difficult circumstances, keeps us going.

Q: Is there anything about the charity you’d like to see change?

A: I’d like to see more emphasis on reaching out to more families and fundraising in Swindon and Wiltshire. Expanding our reach would enable us to help more families in need.

Q: Finally, is there anything you’d like to say to supporters?

A: A big thank you to everyone who supports us. Your support enables us to do a job that is rewarding, challenging, and such a big part of our lives. Thank you for making a difference.

Mary’s relationship with Hope and her family exemplifies the deep connections formed through the support provided by Jessie May. Despite the challenges of caring for a nonverbal child with complex needs, Mary’s dedication shines through, emphasising the importance of trust, routine, and genuine interactions.

Our photos capture heartwarming moments between Mary and Hope, showcasing the joy and comfort found in simple acts like reading together. Such moments highlight the compassionate care provided by Jessie May and also serve as powerful reminders of the positive impact on the lives of families facing adversity.



Mary explains the value of building personal relationships with families, allowing for tailored support that goes beyond just medical care. Despite the emotional challenges, Mary finds strength in her team and the knowledge that their efforts truly make a difference.

Our year in numbers

82% of nursing visits made at home, **+8% Increase** with more in hospitals and elsewhere



296 texts sent in support to our families

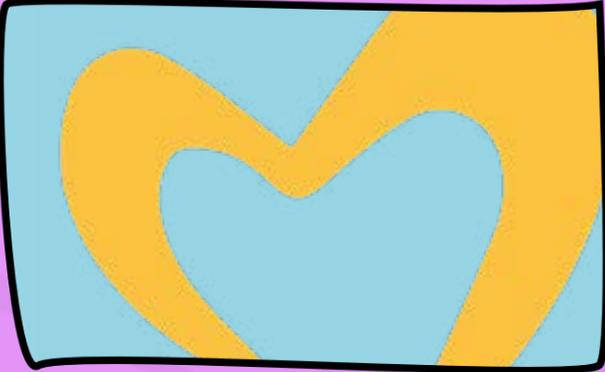


158 families supported by Jessie May



155 visits made to children in hospital **+70 Increase**

4 family events hosted by Jessie May

50 families supported through bereavement



8 Purple Group meetings (peer led bereavement support) held



87 bereavement support visits undertaken by nurses



1,623 specialist nurse visits made to families in need of respite - over 1300 of these in their own homes **+56 Increase**

11 trustees served during this year, including:

- 3** Jessie May parents
- 2** Medical professionals
- 3** Business professionals
- 1** Finance professional
- 1** HR professional

Key members of our local palliative care network

Avon Children's Palliative Care Network - End-of-Life 24/7 Steering Committee - BNSSG Children's Palliative and End-of-Life Care Strategy Group - Royal College of Nursing Community & Continuing Care Forum - Southwest Palliative Care Network - Neonatal Working Group and Advance Care Planning Group

4,656hrs spent providing direct support to children and their families. **+279hr increase**



11 children joined Jessie May

200 phone calls made to support families in need




1 new honorary president, 1 new patron, 5 new family ambassadors, 3 new ambassadors and 1 new team ambassador!

OUR FUNDRAISING YEAR...

APRIL '23

London Marathon

We are lucky enough to have 14 super dedicated, super fit and extraordinary runners compete for Jessie May

MAY '23

The 12 challenge canoe trip

Lloyd Kembrey and his team take on a three day canoe trip from source to mouth of the river Wye! With a new challenge each month, over 12 months they raise an amazing £27,626

JUNE '23

Rob Walker bikes John O' Groats to Lands End

The Absent Friends tour officially closes having raised a humbling £60,239!



JULY '23

Steve's skydive

One of our Jessie May dads, Steve, jumps out of a plane in memory of his daughter Isla and to raise money for the charity.



AUGUST '23

Noah's Ark family day out

A memorable family day out led by our nursing team - with Noahs Ark opening its doors early for 23 of our families!



SEPTEMBER '23

Battle of Blaize

Our friends at Nine Feet Tall send a team of super-humans to take on the Battle of Blaize, a intense fitness X race at the foot of Blaize castle which raises over £500 for Jessie May nurses.

OCTOBER '23

Bath Half

October sees Jessie May at another great event- the Bath Half Marathon. Team Jessie consists of a mixture of corporate and individual supporters who race the 13.1 mile city centre course and raise a whopping £3,770.

NOVEMBER '23

Sodbury Slog

The Sodbury Slog has been part of the Jessie May calendar for a number of years now with the wonderful race committee having chosen to support our work as their main charity beneficiary. This year we field our biggest team yet, hosted by our fabulous volunteers supporting them.

JANUARY '24

Bristol City Women's Football

Jessie May is the official charity sponsor for one of the BCF games. The team then go onto become a team ambassador for Jessie May.



MARCH '24

Jail and Bail

A very successful fundraiser takes place generating national attention. Involving locking up some of our ambassadors until they raise enough bail money!



Started by a family, for families & now shaped by families.

This year we were delighted to welcome Philippa Brownjohn as our Honorary President. Philippa is the mum of Jessica May Purrington and the founder of the charity, having set up The Jessie May Trust in 1996.

2024 marks what would have been Jessie's 30th birthday and it feels like a very timely moment to welcome Philippa into this new Honorary role.

"It has been 20 years since I had an active role in Jessie May but it has always been in my heart and I have been very much following the charity from day to day to see what was happening. So to be invited back in this role feels like coming home. It's where I belong.

"To have had a Jessie May nurse when Jessica was first diagnosed would have been invaluable. To have somebody who could come in (to our home) and get to know Jessica, get to know us as a family; to answer the questions that you have, when you are put in such an awful position. You don't have a guide book, you don't have people telling you what you can do, so to have a Jessie May nurse, somebody who could come into the home to talk to you, to get to know your child and someone who you could leave your child with would have been invaluable."



What do our families have to say?

100%

of carers feel comfortable with the nurses that visit their children

82%

believe that our respite visits definitely have a positive effect on their wellbeing

100%

believe their child is receiving the best possible care from our nurses

100%

feel our nurses communicate effectively with the children

93%

say it gives them time to spend with their other children

100%

believe our nurses spend time focussing on what their children like to do

88%

believe our nurses improve the mental wellbeing of their children

Insights

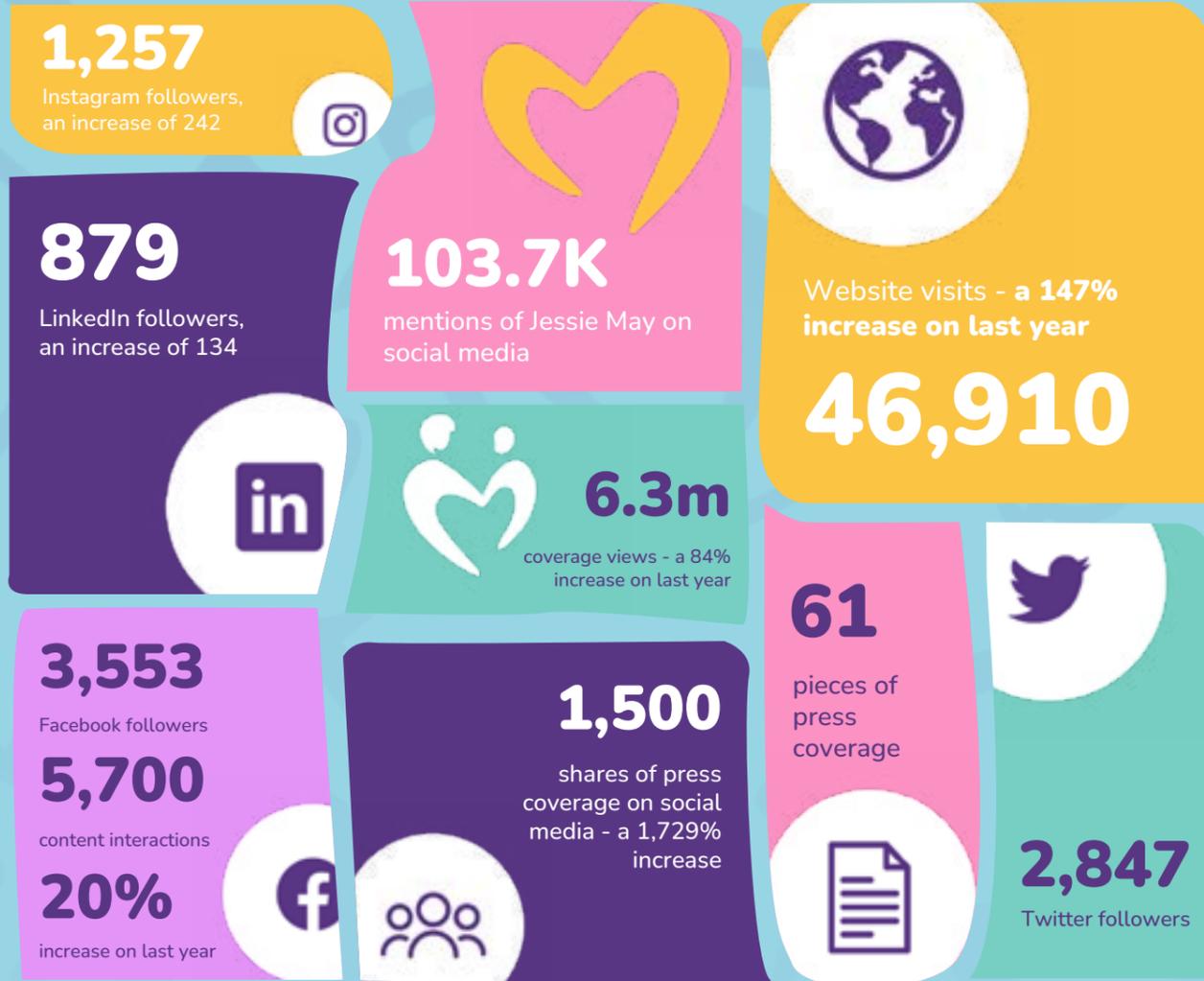
Across the board we have been very pleased with the feedback - with the majority of families who responded happy with all aspects of our service. A pleasingly high level of satisfaction.

One takeaway was that the number of families who completed the survey was lower than we expected. We hope with the introduction of our family engagement team this number will rise. The one other point to raise is the 18% that said they were not sure if our visits provided a positive effect on their mental wellbeing - this is an area we plan on improving when we look at expanding our care offer this year.

In the media

Another active year for Jessie May in the media - with a greater impact across the board

Major highlights include the Sponsor A Nurse campaign in December, the TV coverage of our Jail and Bail event in March and Rob Walker's 'Absent Friends Tour' in the summer.



Social media

Another big year on social media - and it continues to play a vital role in engaging with both sides of our audience, the families we support and the wider community.

All platforms have shown a steady growth in followers with particular success on Instagram in the latter part of the year, due in part to our hugely

successful Jail and Bail event and also the addition of the Bristol City Women's football team joining as team ambassador.

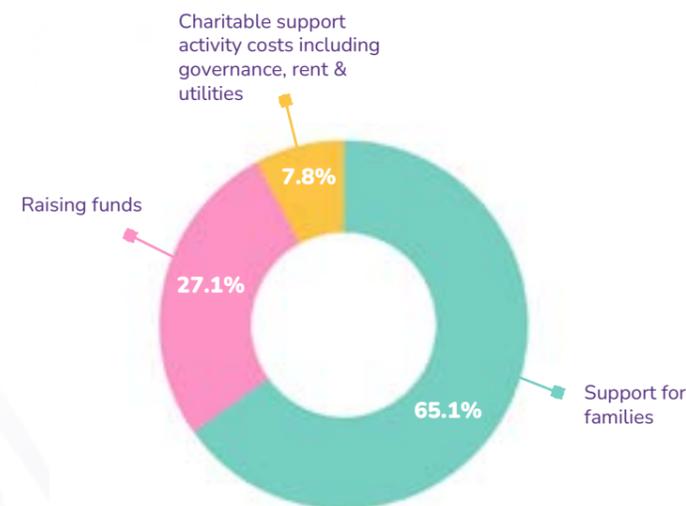
It has also been noticed that our LinkedIn focused news reporting has been praised - with a competitor citing us as a leader in our local sector.

Our finances

We are delighted to announce that this year we raised a phenomenal

£1,717,268

Where did our funds get spent?

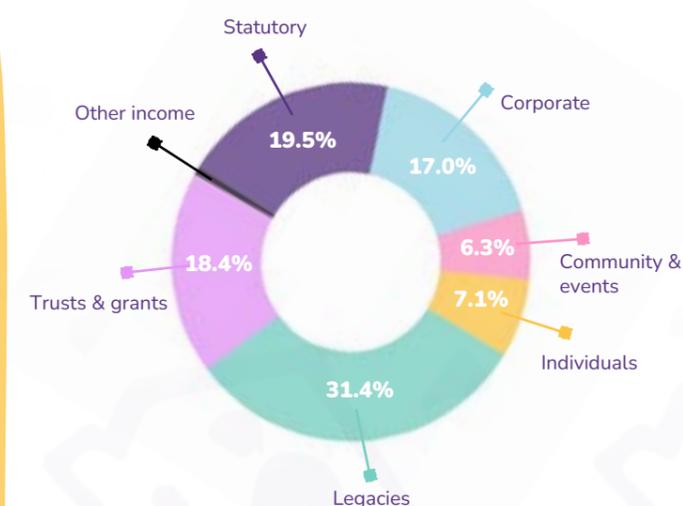


We are delighted to see that direct costs to support families (though our nursing and bereavement offer) has increased by 6% in the last year (16% since 2022/23).

We are continuing our investment into supporting families over the next 12 months so expect this to increase further.

For every £1 spent on fundraising we raised £4.10.

Where did our funds come from?



Our income for 2023/24 was a 3% increase on the year before, making it a record-breaking sum for two years running.

Only 19.5% comes from statutory funding (which includes the Children's Hospice Grant) meaning that the remaining 80.5% relies entirely on the work of our fundraising team and the generosity of individuals, companies, community groups and trusts and foundations, through grants, donations, events and other fundraising activities.

Family Q&A

“The team take the tantrums, the flying food and medical needs all in their stride, nothing phases them!”

- Alex Reuben answers some questions about her Jessie May journey with her twin sons Albie and Louis

Q: Can you share the story of how your family first got involved with Jessie May?

A: Our Lifetime nurse could see that we were exhausted and struggling with caring for the boys. She referred us to Jessie May with a view to getting us some help.

Q: What were your first thoughts and feelings when you heard about Jessie May?

A: Initially I wondered if we would qualify for help as the boys are not on an end of life pathway. However, I soon understood that palliative care is a broad term that encompasses more than just end of life, but also those with complex needs who have a lot of life to live still.

Q: How did you find the support and care provided by the Jessie May team when they first started visiting your family?

A: It's very unnerving to go from living a 'normal' life, to suddenly having lots of professionals involved and people in your home environment. However, the team were so friendly and were amazing with the boys, I felt at ease very quickly.



Q: Can you describe the impact the Jessie May team's visits had on your family's daily life and routine?

A: The Jessie May team come in and take over straight away. They play with the boys, feed them, bath them and get them ready for bed. These are some of the most stressful components of our busy routine and normally means our eldest son is left to fend for himself. Just to have a little break from that routine allows me to have some one-to-one time with the boys' older brother. I can pick him up from school myself and we will often do an activity together.

Q: What differences did you notice in the care provided by Jessie May compared to other healthcare providers your family has interacted with?

A: The team don't just come in and provide help, they care about and advocate for the boys.

Q: Did any particular Jessie May caregivers or nurses form a special bond with your family?

A: All of the team have been lovely, but we have a special bond with Ash.

Q: In what ways did Jessie May become more than just a care provider and integrate into your family life?

A: When you see people making your child feel special and loved, that's different. The team always seem excited to see the boys, which is so reassuring.

Q: Looking back, can you recall any stand out moments or experiences that highlight the impact of Jessie May's support on your family?

A: Caring for any child is not all smiles and giggles, especially children with complex needs. The team take the tantrums, the flying food and medical needs all in their stride; nothing phases them!



Q: What message would you like to convey to the Jessie May team and its supporters based on your family's experience?

A: Charities often have a focus on the children that are unwell or have additional needs. Behind all of those children is a family that is exhausted and continually fighting for support. Jessie May understands that caregivers need some respite. To have a team that can empathise and strives to make life a little bit easier for you, in what can be a very isolated place, is just incredible. Thank you, Jessie May.



Your impact

A few highlights from the fundraising team - what an amazing year!

The Cameron family organise a **festive stomp** from The Downs to Winterbourne every year to raise funds in memory of their little boy Theo. Their total this year is already at a fantastic **£728!**



Sponsor A Nurse Winter Appeal, our most successful appeal to date. The total amount raised was a staggering **£38,160!**

2023 saw Lloyd Kembrey and his friends take on an incredible series of 12 challenges and raise **over £39,690 for Jessie May**. It was amazing to share their journey and there is no doubt they pushed themselves out of their comfort zones on more than one occasion! They are also the recipients of our inaugural **Above & Beyond Award** - which recognises a group of fundraisers that have surpassed all expectations in their contributions to the charity. Well done Lloyd and the team!



A few important thank yous

To the generous trusts and foundations that provided funding in 2023: your support has made an enormous difference to our children and families. We also extend our sincere thanks to the compassionate people who have generously included us in their wills; James Short (an ex Chair of Trustees & an ambassador) and Mrs G Jones. Your wonderful gifts will have a lasting impact on the lives we touch.

How you can make a difference



Fundraise

Join the team and fundraise for Jessie May - our fundraising pack is full of ideas on how to get involved and the events calendar covers all the major events you can take part in.



Organise your own event

From ice skating races to bake sales - organise your own thing to raise some funds for Jessie May. We are there to support you every step of the way.



Spread the word

Follow us, share our stories, and shout out Jessie May on your own platforms. Together we can make a difference.



Volunteer

Donate your time to us by volunteering to help at events. You can cheer on the squad, attend a Bristol City women's game, spread the word and more.



Donate

Make a donation through our website. We promise to spend your donation helping children and young people, and their families, so that they don't have to face life-limiting and life-threatening conditions alone.

You can also follow us on:



@jessiemaytrust



The Jessie May Trust



Jessie May



Get in touch

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Jessie May
Children's Hospice at Home

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