

Healthcare in prison: How to support your loved one

Q1 24/25 Listening Report

6th July 2024



Photo credit: Andy Aitchison



About this report

Pact's quarterly Listening Reports give families a public voice. These reports share what families have told Pact about their experiences of supporting their loved one with health needs in London prisons in the previous three months. They reflect what families have said to us and are written in partnership with our team of family representatives.

We follow a process to make sure we represent families' experiences faithfully and with integrity, without spreading misinformation or causing unnecessary alarm. When an alarm does need to be raised about something families have told us, Pact and NHS London do this immediately through our safeguarding channels. We work collaboratively (rather than in a wholly independent way) with a view to improving outcomes wherever we can. You can find more information about [how we work](#) on our webpage.

Families' comments are not, as standard, subject to independent verification where they relate to reported actions or inactions of third parties. There is a process in place to ensure that clinically serious cases that are raised by family members are escalated, corroborated and reviewed where possible.

In almost all cases, we have limited the issues raised in the report to those that are in the direct remit of healthcare providers and NHS London. However, on occasion, broader issues have been included. Whilst we appreciate these are not in the direct control of healthcare providers, these have been included to provide broader context about what families are telling us about the health of their loved-ones.

All names have been changed. Case studies are reconstructed from notes.

Foreword

If you have a loved one currently inside a London prison, then this report is for you.

Over the last year we've spoken to over 1000 family members about their experiences of supporting their loved ones with health needs in London prisons. Time and again, we've heard families describe feeling left in the dark, their sense of powerlessness and concern for their loved ones' wellbeing.

If you are facing those challenges yourself, you're not alone.

Like all our Listening Reports, this report summarises what Pact has heard from families over recent months – in this case, from late winter into spring 2024 (29th January – 29th April 2024). We publish Listening Reports regularly and our [online archive](#) summarises what we've heard from families whose loved ones are at HMP Belmarsh, HMP Brixton, HMP/YOI Isis, HMP/YOI Feltham, HMP Pentonville, HMP Thameside, HMP Wandsworth or HMP Wormwood Scrubs.

This time, we're not only highlighting themes in what we've heard from families, but sharing back to you how NHS London and healthcare providers have responded when we've raised common issues with them.

We're sharing our top tips and passing on some of the background and explanations we get given when we tell healthcare providers and the NHS about families' experiences.

Families regularly tell us that they simply don't trust the authorities and are sceptical about the some of the explanations they are given. Perhaps part of you might feel sceptical about some of the explanations in this report too – and we understand why you'd be wary, in the circumstances. We've written this report in partnership with families who have their own loved ones inside, and hope the information is useful as you piece together what's going on and make your own decisions about how to support your loved one.

Wherever you are on the journey of supporting your loved one through a prison sentence, we hope that by hearing the stories from others, you'll get a sense of how other families are walking these paths too.



If you currently have a loved one inside a London prison, this report is for you.

Our Listening Activities



Each quarter, we listen through many different channels of communication so families and carers can share their experiences in a way that works for them.

In a new activity, this quarter we were also able to run a series of focus groups to hear from healthcare staff about their experiences of engaging with families.

Listening activities 29th January 2024 – 29th April 2024	No. engaged	Notes
Family Team Members take an active part in shaping the service, including through our active Telegram group.	19	Consulted throughout the quarter: 11 Family Team Members (FTMs), 1 currently being onboarded. 7 Community Members on Reserve.
Semi-structured interviews at Visiting Centres.	202	Interviews at all visiting centres. 23 visits in total.
People share their experiences in a safe space with others in similar situations at family forums .	20	Coffee mornings in February, March and April
Bespoke outreach to target more marginalised and disadvantaged groups .	4	Via discussions with Muslim FTMs over Teams
Families and carers send an email to our functional mailbox .	19	7 unsolicited emails, 12 emails responding to our messages
Families and carers book 1:1 online video calls or request phone calls with the team.	3	Bookings initiated by families
Family and carers have representation at 'Listen to Families' team meetings .	22	Family Team Member attendance at monthly online meetings.
Paper surveys are completed by families and carers at Visit Centres.	17	15 from HMP Brixton, 2 from HMP Wormwood Scrubs
Prison healthcare providers share their experiences working with families in focus groups .	17	4 focus groups with Heads of Healthcare, Deputy Heads of Healthcare & frontline staff via Teams
Total engagements for quarter	322	
Mailing list	144	Plus 26 where our emails bounce back

What we're hearing: Positive stories

It can be very worrying when your loved one has health issues in prison, but we meet families who say they've had positive experiences and that their loved ones are being well looked after.

It's not the case that because your loved one is in prison, they'll necessarily have a bad experience with healthcare.

Some background:

Healthcare providers and the NHS tell us that they can't always give updates to families about their loved ones' care (see slide 7 for more about this). This means that you won't always hear from them about good news – for example, if your loved one has an appointment booked or has received their medication.

Of course, your loved one will know for themselves what their experience has been – but it's possible they don't have the full picture either. For example, for security reasons, they won't be told if they have a hospital appointment booked on the outside. Due to data protection, security or communication issues, they won't necessarily be aware of efforts that have been going on behind the scenes to try and help them.

As the next slide shows, across 1000+ interviews with families, we've found slightly under a third have something positive to say about their experience (even if their experience was mixed).

Our top tips:

- **Keep in touch with your loved one** to get updates about their care. Whilst the prison and healthcare teams have limits on the information they can share with you, there are no rules stopping your loved one from telling you about their own health.
- **Where possible, try to keep an open mind.** It's easy to assume the worst, especially if you don't have much information, but things might not always be as bad as they seem.



Sarah*

'My partner started therapy since being here. He has PTSD and depression, he asked for therapy, and got an appointment quickly. He is in good hands now. He has medication for his mental health... Our relationship has been better since he's been in therapy because we're both good individually.'

Dan*

'He has ulcers and had been coughing up blood. They found a shadow on his lung. He is being taken care of and is being taken back and forth to hospital. He is waiting to find out what's going on and has been waiting for a month... I'm, happy with his care.'

Jane*

'My son has a megacolon and had to have an operation earlier in life. Any pressure applied to one side of his stomach could be fatal. Prison officers know not to apply pressure to this area if they need to restrain him.'

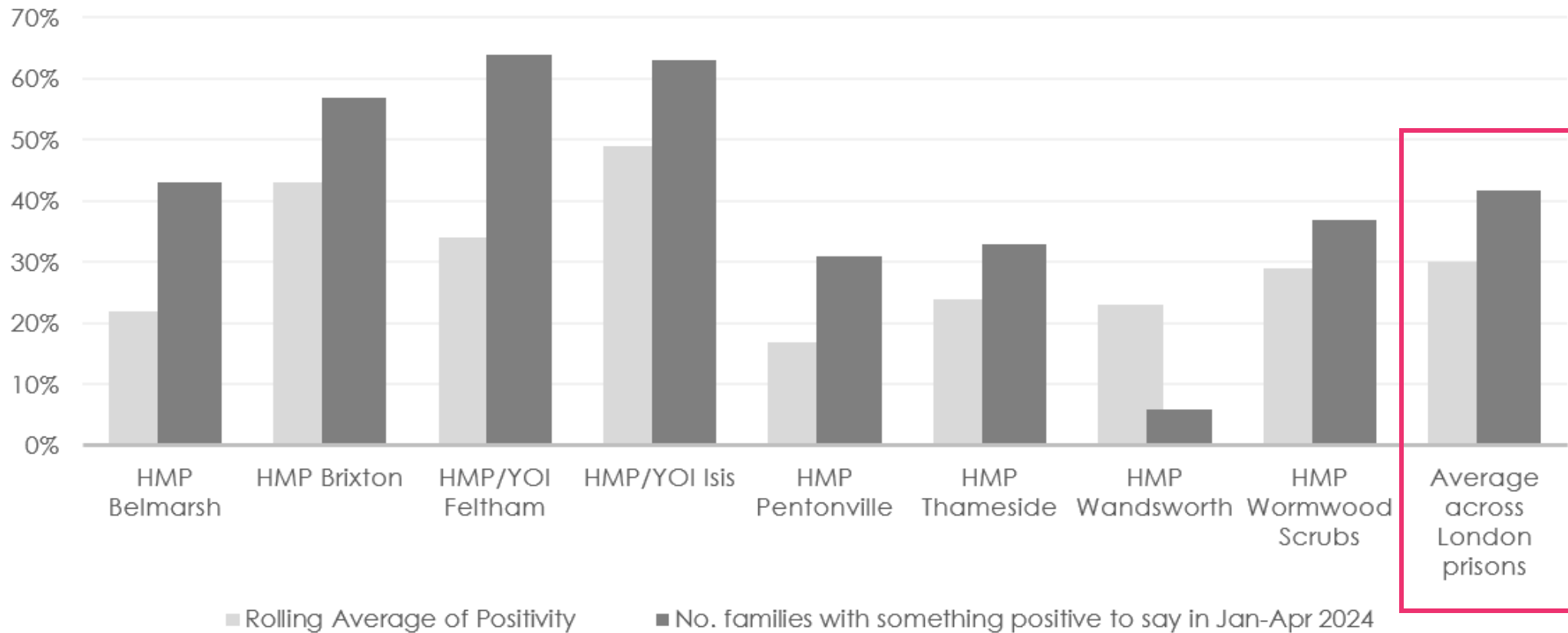
Victoria*

'He was due to have an MRI 2 days after he went in. They organised it for him, and I was pleased with that. I personally sent all of his previous medical records to the prison because it seemed like they weren't able to access anything. That seemed to work, and now he's due surgery [...] It's not all bad! You can't always complain!'

Prevalence of positive comments: Variations by prison

In the last three months, out of the families we interviewed who had experience with prison healthcare, **over a third (41%)** had something positive to say about their experience. This is higher than the average across all our data so far (30%).

The label 'Something positive to say' includes both 'wholly positive' experiences and those who had 'Something positive' to say (at least one positive element to their experience). Experiences categorised as 'something positive' are not necessarily 'positive on balance'.



The data represents subjective experiences and is not an overall assessment of prison healthcare quality. Differences in positivity scores are likely affected by the scheduling of wing visits, as well as a range of other factors. Please see the appendix for further data and methodological notes.

What we're hearing: "They won't tell me anything"

Feel like you're getting stonewalled? You're not the only one. It's very common for family to be told by prison or healthcare staff that they can't share information with them.

For many families, this feels like being fobbed off. Not having your questions answered can be frustrating and many families aren't sure whether the authorities are being genuine when they say they can't tell them anything.

Some background:

Healthcare providers and the NHS tell us that there are a number of reasons why they can't always talk to families about their loved ones' health. To start with, there are security issues to consider - the staff must check who you are and if there are restrictions on them having contact with you.

If you are cleared from a security point of view, the next big barrier is that your loved one has to give consent for the healthcare team to discuss their medical information with you. Of course, some people prefer to keep this private – and if your loved one refuses to give permission for you to know about their confidential health information, the healthcare teams must respect their wishes. Otherwise, they'd be breaking the legal frameworks and professional guidance that all healthcare staff have to follow.

There are exceptional circumstances in which confidential information can legally be disclosed without consent – however these are extremely rare. Of course, there might also be other reasons why you can't get information (for example, staff capacity), but if your loved one doesn't give permission then you almost certainly won't get information out of the prison regarding their health.

Our top tips:

- **Ask your loved one to give consent for their health information to be shared with you.** Explain why this would be beneficial and talk through any concerns with them. Ask them to request that their consent be noted on their records. This means they will have to speak to medical staff themselves.
- **Concentrate on getting information into the prison, rather than getting it out.** Consent is not required for you to tell the healthcare team about your loved one's medical history, their needs, risk-factors etc.
- **Check the rules for yourself** - this short guide has a summary of the [legal instruments and policies](#) that healthcare staff have to follow on patient consent, data protection and privacy.
- **Call the Prisoners' Families Helpline** on 0808 808 2003 for confidential support, information and advice.



Pippa*

'I rang Safer Custody because I was so worried about him, but it took them a week to call me back and even then they said they couldn't tell me anything... You can't get an answer. You ring every number.'

Mary*

'The communication is zero. There just isn't any – if there is, it's all wrong information. It's frustrating, it's exhausting.'

Amaya*

'You call for help and you just keep hearing "No". It feels like some of them are on a power trip.'

Margaret*

'No communication goes on here. No one helps you with your questions when you call.'

What we're hearing: "Nobody's listening"

Families often tell us that nobody listens to either them or their loved one when they raise concerns about health issues. Many find themselves phoning or writing to the prison multiple times. Some families resort to getting solicitors, specialist consultants or MPs involved as they try to get their voices heard.

Some background:

Healthcare providers and the NHS tell us that the pressures they are under means that it's not always easy for them to respond to families. Time constraints and the priority of delivering patient care limit their ability to liaise with families. They sometimes feel blamed for things that aren't in their control.

Healthcare teams have told us they recognise that some families and carers know their loved ones best and have valuable insights that will help them deliver the right care. If you have been a primary carer to your loved one for a long time; they have a complex health condition; lack capacity or have a particular vulnerability, then it's more likely that you'll be seen as offering a perspective that adds value to what your loved one could say for themselves. Families usually also find they're able to be more involved if their loved one is under eighteen.

Healthcare teams tell us that abusive messages are unwelcome – and they are often having to sift through lengthy messages to get to the relevant details. They say it's easier to listen when families communicate concisely and respectfully. They agree that staff should be polite and respectful to you and your loved one and say they would investigate where poor treatment was reported.

Our top tips:

- **Be polite and concise.** Don't get angry or make accusations. Keep your cool, even when provoked. Try to stick to the facts.
- **Describe your credentials as a carer** so the extra knowledge you bring is clear. Provide relevant documents.
- **Ask a professional** to raise issues for you, such as a solicitor, GP or specialist consultant. There is information on how to complain on the [Prisoners' Families Helpline](#) website.
- **Remember names.** Asking people's names and thanking them personally can sometimes help break down barriers. It also means any rudeness can be investigated.



Paul*

'While he was in, he was in desperate need of medication [...] He can be very violent and aggressive without them. The healthcare team looked at his file and told him "You don't need that medication, and you can't have that medication". We went to a [...] GP and had him write in and make a formal complaint about the doctor. After that, my son got the medication he needed within 24 hours.'

Aisha*

'He was stabbed in leg, and it took a long time for him to [...] be taken to the hospital. He put in a request for physio, and it took two months for him to get an appointment. I spoke to the prison and had our lawyer speak to them as well. It was only after the lawyer contacted them that his care kicked in.'

Monica*

'Trying to get anything is ridiculous. You have to do everything yourself... My son has been suffering with his mental health since December. I have written to my local MP, I have reached out to Carer Concern, and I have written to the governor here, and there's been no response. I did get a response from my local MP, but it was a complete brush off.' (see note 1)

Note 1: In March 24, Safer Custody checked on Monica's son and reported that he was "fine".

Jackie*

'My husband has diabetes and needs regular blood tests, but this hasn't been happening. When I ring up, I get rude treatment and am simply told, "He is on the list"... I've complained to healthcare, but sometimes they'll just put the phone down on me. They just hang up on you, and you're forced to keep ringing and ringing.'

What we're hearing: "Everything takes a long time"

Whether your loved one requires dental treatment, mental health support, a hospital appointment or has another health issue in prison, they may find themselves having to wait for care. It can be hard for families and their loved ones to tell whether this is unavoidable, or because something has gone wrong.

Some background:

Healthcare providers and the NHS tell us that as the overcrowding in prisons gets worse, demand on prison healthcare services intensifies. Healthcare teams are understaffed for the number of people who need care; and the prison is understaffed too. Healthcare staff can't provide care without help from prison staff (for example, to unlock prisoners from their cells), so a bottleneck in one part of the prison will create a bottleneck in healthcare too. If one cog stops turning, the whole system can jam up.

Healthcare teams also highlight that there are pressures across the NHS, and it's not uncommon for members of the public to have to wait for healthcare in the community too.

It is wise to have realistic expectations, but it is still vital for families to raise issues on behalf of their loved ones. Healthcare teams tell us they need to know when important care hasn't been given, especially when a situation has reached a crisis point.

Agata*

'Before he came to prison he cut himself very badly, all up his arm and severed many nerves. The physio said they need to book him a specialist appointment outside, but he still hasn't had one and it's been five months.'

Our top tips:

- **Keep notes** of any contact you or your loved one have with healthcare team and the prison, so you have a paper trail and accurate timeline.
- **Reach out for help** if you are [worried about a prisoner](#), especially if things reach a crisis point.
- **Encourage your loved one to take care of themselves** as much as possible whilst they are waiting. For example, by exercising, taking any prescribed medication, eating meals, staying clean and sober, and being productive.



Hannah*

'He banged his head and hasn't felt right since – he keeps getting dizzy and has a really bad headache and lump on his head, and thinks he has a bleed on the brain or concussion. He has put in an app and talks to me about it every day, but he hasn't received any help.'

Amelia*

'He has cystic fibrosis and is Type 1 diabetic and he's meant to be taken to hospital for lung checks every ten or twelve weeks. He's only been taken once during thirteen months in prison.' (See note 2)

Note 2: In March 24, NHS London fed back to us that Amelia's loved one had an upcoming hospital appointment.

Molly*

'He's doing really bad actually. He's asked to speak to the mental health services and sent in about five apps and has been waiting [...] He hasn't been contacted so he doesn't even know if he's on the waiting list.'

Claire*

'He has asthma and struggles to get refills for his medication. When he puts in an app to get the refill, it takes a long time.'

Jan*

'He's 25 and has Type 1 diabetes. When he came into prison, it took two months for him to get the care he needed – it was quite stressful for him.' (See note 3)

Note 3: In March 24, Safer Custody said they would pass Jan's son's issue on to the healthcare team and confirmed he would have to wait for his appointment.

What we're hearing: "He won't ask anymore"

Some people's loved ones lose faith and feel that making health apps isn't worth it. They decide they would prefer not to ask for care in prison, rather than have the uncertainty of not knowing if they'll receive the support they've asked for. Others say that the care available in prison isn't suitable and choose not to request it.

Some background:

Healthcare providers and the NHS tell us that lack of patient engagement is a common reason why people in prison don't receive care. Of course, if patients aren't willing to step forward and request care – or if they refuse care when it is offered, then it's not possible to deliver healthcare services to them.

We've been reassured that, whatever the challenges of delivering care in prison, the healthcare staff still have the same level of qualifications and accreditations that all health professionals must have across the NHS. They must follow the same rules and regulations as other doctors, nurses and clinicians – and their licence to practice will have been granted by the same professional bodies. There are regulators who inspect their services and check whether the care they provide is high-quality and safe.

It's understandable that your loved one might feel hesitant, but they might end up receiving care more quickly if they request it in prison, rather than waiting to ask when they are back in the community.

Our top tips:

- **Don't give up.** Other people have been successful in getting care they need in prison.
- **If necessary, ask on behalf of your loved one.** Call Prisoner Health Information and Liaison Line (0117 240 1193) to get a message through to the healthcare team.
- **Build your loved one's self-esteem** and let them know that, regardless of what they've done, they still deserve to be cared for. Give them encouragement and remind them that not all staff interactions will lead to a bad experience.
- **Come to our monthly Coffee Morning** to meet people in the same boat and benefit from shared experiences (Contact listenstofamilies@prisonadvice.org.uk for details).



Maria*

'But he's gotten to the point where he doesn't put in any requests for mental health help because it takes too long for anything to happen.'

Jing*

'He has [learning disabilities] and has been in prison for almost a year. A [learning disability] assessment has never happened. He asked twice about it, but then gave up. Neither of us have put in a complaint because we don't think it would be dealt with appropriately.'

Kim*

'He's been ill before, and no one's done anything about it. He told officers he wasn't feeling well but because no one did anything, he figured there was no point in asking for help. He figured he would just get over it on his own.'

Edith*

'My husband came into prison with a hernia, and nothing has been done about it for a year. It's because he doesn't want it operated on because he doesn't want to have to heal in a prison bed.'

Monica*

'My son is quite reserved. He won't put in an app to see a doctor, and I can encourage him to, but I can't do it for him... Because he presents ok, he is said to "not fit the criteria" for mental health care... He's young and he's not going to show any vulnerability, but I know his mental health has deteriorated.'

What we're hearing: "They say it's not their department"

Many families have a sense of being passed around the houses as they try to get help for their loved ones. It's not always easy to know which door to knock on – and systems can be slightly different from one prison to another. It's common to be told that, even if an issue is affecting someone's health, it isn't the healthcare department who can help.

Some background:

Healthcare providers and the NHS tell us that a high proportion of the issues that undoubtedly impact on people's health in prison are not in the remit of prison healthcare teams.

To name just a few examples, issues such as cell bells not being answered; prisoners not being escorted to hospital appointments; lack of healthy food; unsanitary conditions; not being able to make phone calls to family; lack of warm clothes or problems with visits are considered 'prison side' issues. The people who could ultimately resolve these problems will not be employed in the healthcare team.

Healthcare providers describe themselves as 'guests of the prison'. They work in partnership with prison colleagues but can't call the shots on prison side issues. It's helpful when families are conscious of this; avoid getting into a blame-game; and make it easy for staff to pass their issue on to the right department.

Many issues may affect health, but sit with the prison (not healthcare):

Orelene*
'They don't listen when a prisoner presses the buzzer. If they [prison staff] don't feel like it's urgent they don't care.'

Our top tips:

- **Do your best to knock on the right door** - ring Prisoners' Family Helpline on 0808 808 2003 for guidance, or Prisoner Health Information and Liaison Line (Call PHILL) on 01172 401193 for healthcare issues. Don't give up!
- **Take notes** – record the names of who you've spoken to and what has been said in your interactions
- **Put your issue in writing** in a concise, factual email, so it's easy for staff to pass accurate information to the correct department.
- **Take it step by step** - Use every contact to get one step closer to help. Keep a record of who you've spoken to and try to approach every interaction as constructively as you can.

Lisa*
'His mental health is dipping at the moment due to me being barred from visits for no reason. They've given me no information about why or how to challenge it – but it's a misunderstanding.'

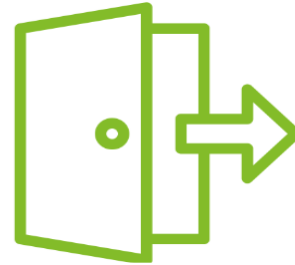
Tom*
'He'll ring the buzzer [from inside his cell] but nobody comes. He has no ability to get any help.'

Maxine*
'There are no healthy food options during visits – it's all chocolates and fizzy drinks. Without us topping up his money all the time, I'm sure he'd be hungry.'

Tori*
'The situation with his property is getting him down. He was brought here six months ago [in the summer] but his clothes have only just been approved. He's been cold all through the winter.'

Harpreet*
'He suffers from schizophrenia. The window is broken in his cell and it's cold at night, which interrupts his sleep [and makes his delusions worse].'

Shaista*
'He says it's depressing in here. The credit situation is hard for him. He has to choose between using money for food and using it for phone calls. It affects his mental health.'



Q1 Inequalities Spotlight: Islamophobia in a custodial context

In each of our Listening Reports, we shine a spotlight on how a different aspect of intersectional inequality affects families' experiences of prison healthcare*. This quarter, Ramadan fell within our data collection period, so our Inequality Spotlight focuses on experiences of Islamophobia. We held discussions with our Family Team Members of Muslim faith to identify key themes, experiences and consequences of Islamophobia within the prison context.

Key Take-Aways: Ask questions, Don't assume, Be kind

Most instances of Islamophobia arise from misinterpretation and misunderstanding. Speaking to Muslim prisoners about their faith can help build healthcare staff's understanding. Remember that it's ok to ask questions!

- **It is important that prison healthcare staff are familiar with different faiths, cultures, and common practices.**

'In prison, Muslims might worry that their actions- whether religiously motivated or not- could be misinterpreted by others. They feel they must hide parts of themselves or not engage in important aspects of their culture for fear of having it used against them.'

'People don't understand that these are basic things in our religion- it's a normal thing to do. Someone calls a prayer, everyone comes together, and they pray. It's not "influencing".'

'Praying 5x a day, keeping long hair and a long beard, memorising the Quran are not extremist activities. They're everyday practices, some of which are very highly regarded in our religion.'



- **Healthcare staff should consider an individual's personal and cultural background and the situational context before they make assumptions.**

'My son is autistic, so he's nervous about asking anyone to cut his hair. He doesn't like to be touched, so he'd rather just have long hair. In addition to this, one of the Prophetic ways is to keep long hair, therefore he has another reason to keep long hair. There's no need to focus on his hair and make anxiety-inducing comments about it.'

'If I were a White person, I don't think that would've happened. I feel I was treated that way because of the colour of my skin.'

'The more religious he got and the more knowledge he gained from his religion, the more he was considered a high security risk. He was watched more, followed more. They labelled him an "influencer", and he felt like he had to hide parts of himself, cut his beard, internalise his faith.'

- **Making culturally sensitive accommodations for Muslim prisoners and their families makes a huge difference for their mental health and wellbeing.**

'Islamophobia creates a domino effect- you lose trust in the system, which impacts your mental health and, in turn, the mental health of your family.'

'During Ramadan, they prepared special meals to break the fast and were very accommodating to my son. That made a huge difference to us. We see he's being taken care of, and that puts us at ease. I can sleep and eat now because I know he is ok.'

'If my son didn't have his Quran, he would be so frustrated and angry. Being able to practice his faith is his medicine for everything.'

*Previous reports have included a focus on neurodiversity, racialised communities, and Gypsy Roma and Traveller Communities.

Conclusion

Whatever you're doing to support your loved one, it will be making a difference. Even if you feel like you aren't getting very far with changing things, it will give your loved one strength just to know that someone is out there, sticking by them and doing their best to help.

Our overall advice would be:

- **Keep going and take notes**
It might be a long journey, so take things one step at a time. Take written notes of the efforts you and your loved one make to deal with issues – for example, note down names, ranks, dates, action points and summaries of conversations. Keep a paper trail – this will be useful if you have follow-up conversations or you need to raise a complaint later.
- **Take care of yourself**
The stress of the situation will probably take its toll on you too, so make sure you have as much support around you as you can. There will be limits to what you can do – be kind to yourself and look after your own wellbeing too.
- **Know that you are not alone**
There are tens of thousands of families in England and Wales who are in a similar situation of trying to support their loved one with health needs in prison. Email Pact at listenstofamilies@prisonadvice.org.uk to connect with our friendly team of families who are in the same boat – our coffee mornings offer a safe space for you to get support without being judged.

Get help



In an emergency, phone the prison and ask to be put through to the orderly officer or Duty Governor.



If you have a concern about the wellbeing of a prisoner that is urgent but not life-threatening, contact the prison's Safer Custody team. Look up their contact details via the [Prisoners' Families Helpline website](#).



If you are concerned about the health of your loved one and they are currently in HMP Belmarsh, HMP Brixton, HMP Pentonville, HMP Wandsworth or HMP Wormwood Scrubs call Prisoner Health Information and Liaison Line (Call PHILL) on 01172 401193 to get a message through to the healthcare team.



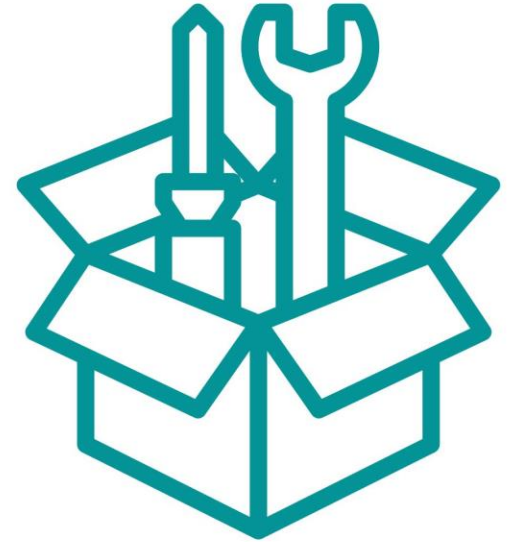
For general questions, information or advice, visit the Prisoners' Families Helpline website or phone for free on 0808 808 2003.

Recommendations

All our Listening Reports include recommendations to NHS London and healthcare providers. These identify the next steps in the journey to improving prison healthcare and ensuring families and carers have a better experience.

- 1. NHS London and healthcare providers should work with Pact to deliver the Family and Carers' Charter for Health and Justice; and measure how far the Charter is being delivered**
 - a. Heads of Healthcare should tell their teams about the Charter and display the commitments on a notice board in their departments.
 - b. NHS London should work with Pact and healthcare providers to agree a monitoring system for the Charter and its line of sight to commissioning processes. This should include an agreement on data-sharing so that delivery of the Charter can be measured.

- 2. NHS London and healthcare providers should support Pact as they lead the production of 'Your Guide to Prison healthcare: By Families for Families'**
 - a. Those who attended the workshop on 4th June 2024 should read and offer comments on the notes, once these are circulated by Pact.
 - b. As we follow the same 'how we work' process as is used for Listening Reports, NHS London, Healthcare Providers and Pact should adhere to the agreed timelines.
 - c. Pact should hold sign-off and publish the guide on our website.



Acknowledgements and thanks

We are grateful to all the family members who shared perspectives with Pact and have entrusted us with their stories.

Whilst this report only reproduces a fraction of the experiences that families have shared, everything we've been told has added to the depth of our understanding. Some family experiences have been fed back in private (rather than publicly), and all data has been recorded, in line with GDPR, and contributes to the picture that *Listen to Families* is building.

On several occasions, listening to families led to immediate action to improve outcomes for families and people in custody. A big thank you to colleagues who responded to safeguarding incidents, and to the visits centre staff who facilitated our data collection.

Many thanks to NHS London and healthcare providers for reading and commenting on drafts of this report. In response to their written input, 2 amendments were made to the text. There were no redactions.

We're grateful to NHS London for commissioning this pilot programme and to healthcare providers and for attending a workshop to share their thoughts on 4th June 2024. Without NHS London's support, this Patient and Public Voice programme would not exist.



To hear more or to discuss this report, please contact:

Dr Amy Pollard

Head of Family and Carer Voice (Prisoner Healthcare)
Prison Advice and Care Trust (Pact)

amy.pollard@prisonadvice.org.uk

You can directly [book a diary slot](#)

Our general mailbox is listenstofamilies@prisonadvice.org.uk

Appendix:

Measuring positivity prevalence

Positivity Prevalence: Methodological notes



Each quarter, we measure the prevalence of positive comments regarding healthcare at each London prison.

We review our qualitative interview data for the period and code the interviews as '**Wholly positive**', '**Something positive to say**', '**Negative experience with some provision**', or '**Wholly negative**'.

Having 'Something positive to say' does not indicate that the experience is 'positive, on balance'. Where feedback is a mixture of positives and negatives, we count the interviewee as having something positive to say (rather than giving wholly negative feedback) if they describe a significant positive or satisfactory element to their experience.

Having a 'Negative experience with some provision' indicates that, while a patient received some degree of treatment or accommodation for their healthcare needs, the overarching experience from their families' perspective was negative.

Whether or not a case study was classified as 'Something positive' or 'Negative experience with some provision' is peer reviewed and deliberated within the Listen to Families team.

The statistics represent data points from Q3 (2023), Q4 (2023) and Q1 (2024). We expect to iterate our methodology and build a richer picture over future quarters.

Caveats:

- Our dataset represents the experiences of family members. This is not an overall assessment of the quality of prison healthcare, which would require a wider range of data sources.
- We believe people who have had 'unremarkable' experiences may say less to us during interviews than those whose experiences have been either very positive or very negative.
- Communication issues in prison may mean that families aren't always aware of the resources available or care that has been offered to their loved ones.

'Wholly positive' versus 'Something positive' experiences

Interviews were coded as: 'Wholly negative', 'Wholly positive', 'Something positive' and 'Negative experience with some provisions'. 'Something positive' means the interviewee described at least one positive or satisfactory element to their experience. We excluded interviewees who reported having no experience to share.

Together, 'Wholly positive' and 'Something positive' reviews make up the population of family members who had 'something positive to say' about their experiences with the prison healthcare system.

Similarly, reviews labelled as 'Wholly negative' and 'Negative experience with some provisions' make up the population of family members who had a predominantly negative experience with the prison healthcare system.

Category of Experience in Q1	No. of interviewees	%
Wholly positive experience	31	25%
Something positive to say	19	15%
Negative experience with some provisions	29	24%
Wholly negative experience	44	36%
Total	123	100%
Wholly positive + Something positive	50	41%

Prevalence of families' positive comments

Comparison table

It is more common to find families reporting positive experiences at some prisons than at others:

Prison	No. Families interviewed Jan-Apr 2024	No. Families with something positive to say Jul-Oct 2023	No. Families with something positive to say Oct 2023-Jan 2024	No. Families with something positive to say Jan-Apr 2024
HMP/YOI Feltham	25	1 (33%)	4 (25%)	9 (64%)
HMP/YOI Isis	25	6 (55%)	8 (44%)	10 (63%)
HMP Brixton	25	8 (35%)	9 (50%)	8 (57%)
HMP Belmarsh	25	5 (31%)	1 (6%)	6 (43%)
HMP Wormwood Scrubs	26	9 (45%)	2 (12%)	7 (37%)
HMP Thameside	25	0 (0%)*	3 (27%)	5 (33%)
HMP Pentonville	25	0 (0%)*	1 (9%)	4 (31%)
HMP Wandsworth	26	3 (38%)	5 (42%)	1 (6%)
Total London Prisons	202	32 (37%)	33 (28%)	50 (41%)

Overall, more than half (61%) of the families we interviewed at visiting centres have experiences with prison healthcare.

Of these, over a third (41%) had something positive to say in Q1, which is higher than in the two previous quarters.

*Figures from Q3 are anomalies due to small sample sizes. Listen to Families Visits have since been scheduled to ensure equal coverage of prisons.

Prevalence of families' positive comments

Feedback type across London prisons in Q1 (Jan-Apr 2024)

