

Do you see us?

Carers with no recourse to public funds who are supporting loved ones at the end of their life

A guide for hospice and palliative care staff



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Foreword

We are delighted to introduce this toolkit to you and invite you to explore it further. We invite you to put aside any thoughts that it may not be significantly mainstream enough to warrant your time, or that it is unlikely to offer anything new – beyond your knowledge already related to palliative care, and/or the support of people with no recourse to public funds.

We suggest this for a couple of important reasons. It could be argued that there has never been a time when attention to inequalities around life and death has been more important. As we write this foreword we are in the middle of the coronavirus pandemic, a global event that has highlighted inequalities at so many levels – economic, health, geographic and ethnic, all of which affect the degree to which people succumb and indeed survive the disease.

Of course, such inequalities are not new and there is sobering evidence of a range of inequalities that adversely affect how people die beyond Covid-19, including those related to where someone lives in the world, peoples' sexuality, lifestyle choices and other needs including learning difficulties.

This brave piece of work seeks to redress an area of disadvantage at end of life that is often quite hidden and is relatively uncharted due to its sensitive nature. It recognises the heroic but often unrecognised role of family carers in helping someone to die well, and then the additional challenge they face when they have no recourse to public funds.

The financial hardship often endured, their uncertain position within the legal and social security systems, and their fears about their future and that of their families can only add to the anxieties related to caring for someone who is dying. We know that carers are under significant stress when they adopt this role and the stories emerging in this work confirm that this is increased when people have no recourse to public funds. Our thanks go to all those brave and willing to share their stories with us, without which the toolkit would not be the impactful resource that it is.

The exciting element of this toolkit is the opportunity it affords for new partnership working between people who are expert around end of life and those who feel confident working with people with no recourse to public funds. Neither can help this group of people adequately on their own – each need the other to attend to the double disadvantage facing carers and those they care for. For this reason, it is written in a way that brings their two worlds together, with the person who is dying, their families and carers at the centre. This is the essence of the very best of end of life care and we hope it will encourage all involved to emulate it in their practice.

Finally, we recognise the foresight and courage of St. James's Place Charitable Foundation and Hospice UK in funding this work. Thank you for making it possible.



Heather Richardson RGN, RMN, MA, PhD
Joint Chief Executive, St Christopher's



Claire Henry MBE
No Recourse To Public Funds Project Lead

Our starting point

There are people out there reluctant to ask for help when a loved one is nearing the end of their life. The death of someone close to them is not their only worry. They may not have a roof over their head or any money to feed their family. They may not feel trusting enough to be open about their situation. This is the very real situation that may be faced by carers who have no recourse to public funds (NRPF) and are facing financial hardship.

Nearly 1.4 million people in the UK don't have access to the welfare safety net¹. This 2019 figure represents those that held valid UK visas that would usually have a condition attached to them restricting access to public funds. In reality, this number may be far greater when also factoring in illegal entrants and visa overstayers.

Our starting point is one where...

...not enough people know what NRPF means

NRPF is a condition imposed on someone due to their immigration status. It applies to people who are subject to immigration control, for example:

- those on work, study and family visas coming to the UK from outside the EU
- those who can indefinitely remain in the UK but have a five-year prohibition on claiming any public funds or
- those who have no right to remain in the UK, such as visa overstayers and illegal entrants.

A person with NRPF is prohibited from accessing public housing and specified benefits. There are exceptions to this, and more information can be found in the Resources section of this guide. As an example, hospices are not counted as a 'public fund' and therefore, theoretically, those with NRPF should have little resistance and reluctance to access hospice palliative care in the UK. In reality, this is not always the case.

 **1.4m** Approximate number of people in the UK without access to the welfare safety net

Examples of funds people with NRPF cannot access

- Universal Credit
- Child Benefit
- Carer's Allowance
- Council Tax Benefit and Council Tax Reduction
- Disability Living Allowance
- Social Fund payment, including Budgeting Loan, Sure Start Maternity Grant, Funeral Payment, Cold Weather Payment and Winter Fuel Payment
- State Pension Credit
- Housing allocated through a council's register
- Local authority homelessness assistance.

Note: NHS hospital treatment is not normally free for people who have overstayed their visa, illegal entrants and refused asylum seekers.

Examples of funds people with NRPF can access

- Child maintenance
- Concessionary travel passes
- State school education
- Free school meals
- Legal aid
- Housing rented directly from a housing association
- Some NHS care, including GP services, walk-in centres and A&E departments
- Social services help
- Work-related benefits, such as Statutory Sick Pay, Maternity Pay, Incapacity Benefit and Bereavement Support.

See the [Resources section on page 18](#) for links to further information.

...people with NRPF are routinely discriminated against

Like many non-UK nationals, people with NRPF may face language and cultural barriers which serve as deterrents and obstacles in accessing support. Likewise, those with NRPF also tend to have protected characteristics i.e. low-income families, people from black and minority ethnic backgrounds, women, disabled people, pregnant women, and LGBTQ+ people. Having NRPF further exacerbates the systems of discrimination and oppression which already operate against these individuals.

...there is a distinct lack of data and literature focused on people with NRPF, what their needs are, and how they can best be supported

The literature that is available, mainly from social work, NHS and homelessness services, is limited and insufficient. What does exist tends to focus only on protected subgroups who are very likely to have NRPF, e.g. asylum seekers. The literature concerning how hospices can best support carers with NRPF is non-existent.

There is an urgent need to research and assess how hospices and specialist palliative care units can best support those with NRPF, especially their carers and families. There are too many unknowns with this vulnerable group of people. We cannot even reliably say how many people this is likely to affect. We hope that through education and communication, we can begin to better identify and respond to people's needs.

Our response is to explore how best to support people with NRPF

In 2019, St Christopher's Hospice identified a need to support carers who have NRPF and are caring for someone who is dying. Investment was secured from the St. James's Place Charitable Foundation and a project was established.

Led by Claire Henry MBE, the project aimed to increase understanding and explore the issues faced by this vulnerable group of people. This included identifying the potential number of people affected, what their needs are, and how the hospice and palliative care community can help, working in collaboration with a range of partner organisations.

Many voices were heard from a wide range of backgrounds and organisations, the details of which can be found in the [Acknowledgements section on page 26](#). Please note that names have been changed in all personal stories included in this guide.

The project has resulted in the development of this guide, which is a practical resource for hospices and palliative care providers across England. It will enable professionals to better equip themselves to support people who find themselves in this situation.

An additional guide has also been produced for staff working in migrant centres and related organisations, explaining the help and support that the hospice and palliative care sector can provide.



90% of families with NRPF have at least one British child – these children receive less favourable treatment including being denied access to free school meals



74% of people with NRPF living with 'limited leave to remain' went at least one day where they could not afford to eat a hot nutritious meal – 90% of these were women with children



95% of people with NRPF living with 'limited leave to remain' had experienced severely inadequate and overcrowded accommodation

Sara's story

Sara came to the UK from Sri Lanka and lived with her partner Dinesh and their two young children, aged four and five. Dinesh had full status to work and stay in the UK, however Sara was an overstayer and therefore not legally entitled to remain here. They shared a house with another family with young children, meaning they only had one bedroom for the four of them. The house was extremely cluttered and had a mice infestation.

When Dinesh was diagnosed with head and neck cancer, he became too unwell to work. He was able to claim benefits, but Sara as his main carer was not. The family began to run into more difficulties. The acute hospital referred Dinesh to the local hospice for social and welfare support. It took the team some time to build up trust with the family. Coming up to Christmas time, Dinesh was experiencing a great deal of distress and pain. This was compounded by the very real possibility that he could have a catastrophic bleed. Dinesh was admitted to the local hospice and his family were able to spend Christmas there with him. This meant that the children were able to receive some toys that had been donated, and the family were able to have a special Christmas together in a clean, safe and private environment.

The hospice team discovered that Dinesh and Sara were not married, a situation they kept private and felt ashamed to admit. As Sara had no right to remain in the UK, when Dinesh died there would be a problem regarding Sara's legal status. The best option would be to enable Dinesh and Sara to get married. Unfortunately, Sara needed her divorce papers from Sri Lanka and Dinesh deteriorated rapidly, so getting married was not possible.

After Dinesh's death, Sara had no means by which to support herself; she no longer had access to any financial support, she didn't have a legal right to stay, or the means to secure British passports for her children, and their accommodation was in Dinesh's name. The whole family were understandably very distressed. Thankfully, the hospice welfare and social care team were able to provide support. The team provided support to Sara and her family in many ways, including:

- providing funds to enable the children to obtain British passports
- arranging a volunteer immigration solicitor to take on Sara's case for free and help with her application to remain in the UK

- accompanying Sara to various meetings with the Home Office
- accessing grants for heating, travel, and clothes for Sara and the children
- liaising with the local council, where Sara needed to provide evidence that she was destitute and had nothing in order to access support, e.g. a weekly £20 supermarket voucher and
- accessing support for Sara and the children from the hospice's Bereavement Team.

The local church was also incredibly supportive, with the church warden providing the family with food and school uniforms. The hospice team were also available to provide emotional support for the church warden, as well as Sara.

Sara's right to stay was approved, which meant that she was able to access benefits. However, before any benefit money was received, there was a five-week period where Sara was no longer eligible for food vouchers. Both the hospice and the church supported the family during this time. The landlord gave Sara the tenancy for their accommodation as she was able to claim Housing Benefit. The other family moved out, so she and the children had a self-contained flat.



Why is this important?

Why? Because caring for a loved one is hard enough as it is

Research suggests that carers suffer considerable stress during extensive periods of caring for someone²; carers are twice as likely to suffer from ill-health than non-carers and are 70% more likely to conceal their suffering.

Having NRPF adds additional worries to the mix. Carers with NRPF may not know where they will live after their loved one dies, how they will be able to afford to eat, or to take care of their children.

Why? Because carers with NRPF may go unnoticed

For many reasons, carers with NRPF may not readily choose to disclose their circumstances. However, it is important that they are identified at an early stage to ensure their needs are met appropriately and they are offered specialist advice.

It is important to check whether someone has NRPF when concerns have been raised or when more information has been offered.

Examples of people whose NRPF status should be checked include:

- people whose primary need appears to be for housing
- people working in the sex industry (for example prostitution)
- people living in large groups in rented accommodation
- victims or potential victims of human trafficking
- victims or potential victims of modern slavery
- victims of domestic abuse where there are concerns about immigration status
- people who tell you they entered the country to seek asylum (even if this was many years ago)
- people who tell you they are an illegal entrant
- people who are reported to be an illegal entrant or subject to immigration control and
- people who are from other European Economic Area states.

Source: Haringey, London: *Procedures, Practice Guidance and Tools for Adult Social Care*.
http://www.proceduresonline.com/haringey/adults/chapters/default_chapters/p_no_recourse.html



x2 Carers are twice as likely to suffer from ill-health than non-carers



70% of carers are more likely to conceal their suffering than non-carers

Why? Because hospices are well placed to respond

People with NRPF may be generally deterred from accessing healthcare services and provisions, including hospices, under the assumption that they will be charged, or that the care providers have close relations with the Home Office.

In this respect, hospices and specialist palliative care units are ideally placed to respond. They provide holistic care that is free even for those with NRPF. They are not state funded or state run. Hospices have access to a wide range of professionals and community links that may benefit people with NRPF. This includes social workers, bereavement teams, faith groups and housing organisations.

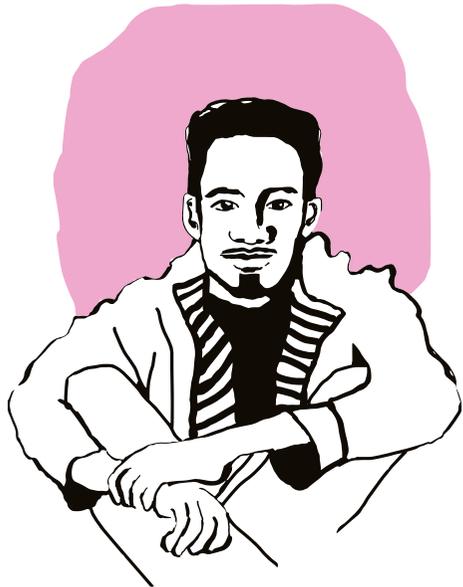
The clinical and social support needs of carers with NRPF are often intertwined. Housing, benefits, social support, and education needs are all important to consider holistically alongside a person's clinical care and treatment. It is therefore vital to engage and work in partnership with community organisations that have specialist knowledge and work in culturally appropriate ways.

It is important to recognise the contribution of voluntary and community sector initiatives in supporting carers with NRPF. By mapping the multiple agencies that are able to assist people, hospices and other services alike can provide a more holistic service that can significantly change people's lives.

Ian's story

Ian was 17 years old and had cared for his father up until his death. Ian had NRPF and subsequently found himself living on the streets. He felt abandoned and alone. Nobody had considered his needs as a carer.

Ian was fortunate to come into contact with a church housing association, who gave him a safe place to stay. As he was under the age of 18, Ian was classed as a minor. The association was able to provide legal advice and support, securing Ian's right to stay in the UK. They also accessed support from the local authority and provided Ian with bereavement support.



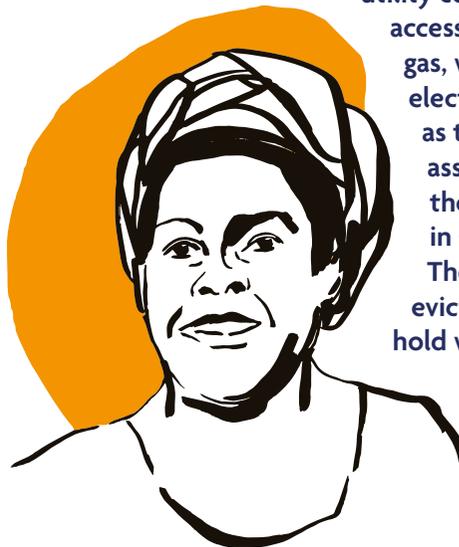
Joy's story

Joy and her partner Charles were from Nigeria. Charles had the right to remain in the UK and worked for Transport for London. Joy did not have right to remain, and when her mum died in Nigeria she was unable to attend the funeral as she would not have been able to re-enter the UK.

When Charles was diagnosed with lung cancer and brain metastases, Joy became his main carer. As they were not married, after his death Charles' family took over the arrangements and repatriated him to Nigeria. Joy did not get the chance to say goodbye and had no access to funds in the UK.

The hospice team supported Joy both emotionally and practically with food parcels and grant applications. They also wrote letters of support to

utility companies to access funds for gas, water and electricity, as well as the housing association where the tenancy was in Charles' name. They got the eviction put on hold while Joy's right to remain case was ongoing.



Isabel's story

Isabel, aged 30, cares for her mother Joanna who has a disability requiring physical and personal care. In addition, Joanna's care needs are increasing as her health deteriorates. They found themselves with NRPF after fleeing the marital home due to domestic abuse.

They received care and support from a local church housing association where they felt safe. The housing association provided support looking into securing accommodation, alongside legal advice in relation to their immigration status. They were also able to help provide personal care for Joanna.



Things to think about

In order to make sure that the needs of carers with NRPf are met, we have brought together two relevant approaches – the total pain approach and the Carer Support Needs Assessment Tool (CSNAT)³. We have added an additional element covering bereavement care.

This section highlights things that may be important to think about in addition to the regular support offered to carers. It largely focuses on carers with NRPf who are experiencing hardship.

Total pain

The concept of 'total pain' was coined by Dame Cicely Saunders, key contributor to the modern hospice movement. She suggested that pain be understood as having physical, psychological (emotional), social, and spiritual components. There is overlap across these four elements, with many of the needs of carers with NRPf being multi-faceted.

CSNAT

The CSNAT intervention is made up of an evidence-based tool which is incorporated into a person-centred approach to assessment and support. It is practitioner facilitated and carer-led. The tool has 14 domains (broad areas of support needs) in which carers commonly say they require support. Find out more at <http://csnat.org>.



Carers first: bringing total pain and CSNAT approaches together

Physical needs

- 1 Managing symptoms and giving medicine
- 2 Providing personal care for the patient
- 3 Knowing who to contact when concerned
- 4 Own physical health concerns
- 5 Equipment to help care for the patient.

Emotional needs

- 6 Having time for themselves in the day
- 7 Understanding the patient's illness
- 8 Dealing with their own feelings and worries
- 9 Talking to the patient about their illness
- 10 Knowing what to expect in the future.

Social needs

- 11 Financial, legal or work issues
- 12 Practical help in the home
- 13 Overnight break from caring.

Spiritual needs

- 14 Beliefs or spiritual concerns
- 15 Bereavement care.



Physical needs

1 Managing symptoms and giving medicine

Carers with NRPF may need help with knowing which healthcare services they can access for free and which may need to be paid for. This applies even more when their relative also has NRPF.

- Are they are registered with a GP surgery? GP services are free of charge

- Are they are entitled to free prescriptions?
- Are they physically able to collect prescriptions, e.g. can they walk to the pharmacy or do they have money for transport? Or can they have medication delivered?
- Do they have funds to buy supplies that are needed, e.g. sanitary products, incontinence pads etc.?

2 Providing personal care for the patient

Carers with NRPF who are facing financial hardship may be living in shared housing, with a lack of privacy. They may not be able to access domiciliary care support or may have cultural considerations about doing so.

- Do they have a shared bathroom?
- Do they have access to laundry facilities?
- Can they afford clothing and toiletries?
- Do they know where they can get support?

3 Knowing who to contact when concerned

People may need reassurance that support is available to help them and help to understand what support they can access free of charge. There may be concerns about cost or about connections to the Home Office. There may also be language barriers to consider.

- Have they got the means to contact people, e.g. access to a phone and money to top it up?

- Do they have any communication needs, e.g. access to an interpreter?
- Do they know who they can contact for help during the night?

4 Own physical health concerns

Carers with NRPF, particularly those facing financial hardship, may be less likely to seek help for their own health needs. They may be experiencing high levels of stress and anxiety dependent upon their wider situation and background.

- Are they accessing health and care services themselves? They may be experiencing lack of sleep, back problems from lifting, or have missed their own appointments
- Do they and their family have unmet care needs?

Equipment to help care for their relatives

People may not know about, or have access to, the support needed in terms of appropriate equipment. Hospice and social care teams working together can help to overcome these challenges.

- Are there grants available for specialist equipment that isn't free of charge?
- Is the person's living arrangement suitable for the equipment needed?
- Do they have any worries or concerns about having such equipment in the home?
- Do they know who to contact about the equipment?

For more information

For links to more information on how best to support the physical needs of a carer with NRPF, see ['Physical' in the Resources section on page 22](#).

Mary's story

Mary and her husband Emmanuel came to the UK from Kenya, with their son Alexander, aged 5. Things didn't go to plan for the family; Emmanuel was diagnosed with a brain tumour and their initial application for asylum was turned down. Mary was unable to work and became Emmanuel's full-time carer.

They were placed in shared accommodation with another young family. Each family had one bedroom, and they shared a kitchen and a bathroom. Their bed had bed bugs and they had to wait for the local authority to come and fumigate

Emmanuel's condition was proving very physically challenging and Mary became overwhelmed. His vision was deteriorating, his memory loss was getting worse, and he was becoming disinhibited, often walking around partially dressed and wandering off when he was left alone. Mary herself was experiencing headaches, low mood and her asthma had worsened.

The family were referred to the local hospice, whose social worker played a pivotal role. They helped to arrange:

- day care and inpatient care for Emmanuel
- support to improve their living conditions
- accessing grants
- referral to a local carers organisation for support
- counselling for Mary and her son Alexander, who was finding his father's condition distressing
- additional school support for Alexander and
- support progressing their case to remain in the UK.

The family were eventually granted leave to remain in the UK, which enabled them to access further help and support, and meant they could move out of the hostel settlement accommodation they were in.





Emotional needs

6 Having time for themselves in the day

Like all carers, those with NRPF may require time to prioritise their own needs and their own wellbeing. They may also feel less worried knowing that their relative is in good hands if they require time to progress their own right to remain case to stay in the UK. This is frequently cited as one of the things that matters most to carers with NRPF.

- Can they access any day therapies or day care?
- Are there any complementary therapies that they can receive?

7 Understanding the patient's illness

Different cultures may have very different views about death and dying. It is therefore important to explore this alongside a carer's understanding of their relative's illness. In addition, some people may have delayed seeking medical treatment due to concerns around possible costs involved.

- Are there restrictions on the hospital treatment their relative can receive free of charge?
- Does the carer have a clear understanding of common terms used, e.g. palliative care?
- Is a translator needed if they are not fluent in English?

8 Dealing with their own feelings and worries

Subsets of people with NRPF, for example asylum seekers and illegal entrants, may be more likely to have experienced mentally distressing events in their past. All carers with NRPF can discuss their mental health with a GP. In addition to worries about their loved one's death, carers with NRPF may also be concerned about:

- their right to remain case
- housing issues
- affording food

- social isolation
- their children's future
- extended family or
- transport.

Building trust and working collaboratively with other agencies is essential in supporting people to deal with their feelings and worries.

9 Talking to the patient about their illness

Carers with NRPF may need support in talking with their loved one about their illness and treatment, being respectful of cultural and relationship considerations. In particular, they may need support in discussing what will happen after the individual dies.

- Does their loved one have concerns about what will happen to their carer/family after death?
- Can any reassurances be given?

10 Knowing what to expect in the future

Uncertainty is familiar to many carers with NRPF. It may help to reduce worries and concerns by discussing what care is free, where the person will be cared for and where they would like to die. Some carers may also like to know what changes to expect as the individual progresses towards death.

- If their loved one is admitted to a hospice, can they/their children stay with them?
- Will the family have access to bereavement care?

For more information

For links to more information on how best to support the emotional needs of a carer with NRPF, see ['Emotional' in the Resources section on page 23](#).

Rana's story

Rana was originally from Mauritius and met her partner Richard, a British citizen, while he was working there. They each had children from previous relationships, and had two daughters together, both now teenagers. They had a good quality of life; their home came with Richard's job, the children went to private school, and they had financial security.

During periods spent in the UK, Rana was on a 10-year visitor's visa, and the children had British citizenship. After a series of heart attacks and a long history of depression, Richard became too unwell to work and the family returned to the UK permanently in 2018. Upon arrival, Rana was seen by Home Office officials as her visitor's visa had expired. She was given entry into the UK and told her status is now settled.

While living in Kent, Rana and Richard were able to claim welfare benefits with no issues. Following a deterioration in Richard's health, the family needed additional support. They decided to move to London to be closer to Rana's daughter from a previous relationship, who was settled there with British citizenship. Here they accessed hospice services.

Unfortunately, when they moved to London, they needed to come off Employment and Support Allowance to claim the newly rolled-out Universal Credit. Rana was refused with the explanation that she has no status in the UK.

Meanwhile, their two teenage daughters were finding it hard to adjust to their new life in the UK and their father's health deterioration. The youngest daughter at the age of 14 suffered with severe mental health issues and was sectioned following self-harm and suicide attempts. Their 18-year-old daughter got involved in a relationship with a man who radicalised her and subjected her to domestic violence. Richard and Rana focused all their efforts on helping their daughters, including seeking police and mental health service involvement.

The family were only eligible for Universal Credit for Richard and their 18-year-old daughter. Money became a struggle and they relied heavily on a discretionary housing payment to top up their rent shortfall. They were in debt and at times also needed to rely on food bank vouchers and any support the hospice could provide, including a donated Christmas food hamper.

They got their local MP involved in their case, however the advice received from the Home Office was very vague. They wanted to sort Rana's status out before Richard died, however with everything else going on they were unable to prioritise this.





Social needs

11 Financial, legal or work issues

Perhaps the biggest area of concern highlighted when interviewing carers with NRPF in the creation of this publication was their legal status. Its importance cannot be understated, as it is often seen as the key to unlock other support, despite being a lengthy and bureaucratic process.

Please note that it is illegal for unqualified people to give immigration advice. Migrant centres offer qualified immigration advisory services which are often provided at no cost.

- Do they need help liaising with their legal team or completing paperwork?
- Have they needed to balance work commitments with caring responsibilities?
- Are there grants available to assist during times of financial hardship?
- Are they receiving support from local churches/migrant centres?

12 Practical help in the home

Carers with NRPF may require the support of multiple agencies, in addition to wider family/social network support.

- Do they have a wider support network?
- Is their accommodation suitable?
- Is social work support being received? What about faith groups, local charities and/or childcare support?

13 Overnight break from caring

As with all carers, it may prove difficult to arrange an overnight break from caring. Services will vary significantly locally.

- Is an inpatient admission appropriate?

For more information

For links to more information on how best to support the social needs of a carer with NRPF, see [‘Social’ in the Resources section on page 22](#).

Patricia's story

Patricia arrived in the UK from the Congo at the age of 63, having experienced the most unimaginable trauma which she finds difficult to talk about. She was seeking asylum and for 10 years had NRPF.

Patricia accessed support wherever she could get it and was helped by a variety of organisations. This meant frequently moving around the country depending upon where she could be accommodated, in what is known as adult related foster care. She was often moved with little notice and was unable to settle for long in one location and begin to make a new life for herself.

Eventually Patricia returned to London where she received help from the Notre Dame Migrant Centre. They provided her with support to secure accommodation, as well as specialist legal advice, clothing, and food. She was also put in contact with a Congolese support group and faith-based organisations, receiving much support from the local Jewish community.

At the age of 74 and finally settled in one place, Patricia was diagnosed with cancer. Her sister, who also lived in the London area, was unable to provide the level of support Patricia needed, and so her GP made a hospice referral.

Hospice staff visited Patricia at her shared accommodation and she also attended outpatient appointments. The hospice supported her with financial assistance to get to and from her appointments and provided emotional support. Patricia was eventually granted settled status, and the hospice social worker helped her to secure a small local authority flat, set up a bank account and access counselling.





Spiritual needs

14 Beliefs or spiritual concerns

Faith communities have a key role to play in supporting carers with NRPF. As with all carers, respecting their beliefs is fundamental.

- Are they currently in contact with faith-based groups? If not, would they like assistance to make contact? If they have no religious faith, they may not wish for any contact to be made.
- Do they need respite so that they have time to attend a place of worship?
- Are they familiar with the person's wishes for after death?

15 Bereavement care

Carers with NRPF may not know where to turn after a person's death. Hospices play a crucial role in supporting families long after somebody has died. This includes ongoing support with legal cases, housing arrangements, and accessing benefits for those that do gain the right to remain.

- If the person is not from the UK, do they want to be repatriated after death?
- Do you have contact details of any relatives abroad that it may be necessary to get in touch with?
- Do they have funds for a funeral, or will they need help accessing support?

For more information

For links to more information on how best to support the spiritual needs of a carer with NRPF, see ['Spiritual' in the Resources section on page 23](#).

Rose's story

Rose and her husband Samuel arrived in the UK in 2018. They were in their 40s and had three children. The family had fled Nigeria following an attempt on Samuel's life and were fearful of further repercussions. An application for asylum was submitted with support from a local migrant centre.

Their living conditions were poor and cramped, and they had little money for clothes, food, or to pay bills. During this time Samuel was diagnosed with cancer. He refused all active treatment and so the focus of his care was palliative. They were referred to the local hospice for support.

Rose and Samuel's faith was important to them, and they believed that prayer would help them through Samuel's illness. The hospice social worker sat with Rose while she prayed, which was of great comfort and helped to build trust.

The hospice convened a multi-agency meeting to determine how best to support the family. This included social work, migrant centre, school, and health care representatives. They were able to access financial support in the form of a grant.

Eventually, Samuel was admitted to hospital and died several days later. The family had no funds for a funeral. Rose did not feel that a publicly funded funeral was culturally appropriate, having to share and be buried in an unmarked grave. Samuel's body stayed in the mortuary for two months while alternative arrangements were made. The local church stepped in and provided a simple and dignified funeral.

The social worker continued providing support to the family in partnership with other agencies such as the migrant centre and the children's school.



External factors to consider

Coronavirus pandemic

The Covid-19 pandemic that is currently facing the UK in 2020 has hit many people hard, particularly those with NRPf. It was reported that the number of people contacting Citizens Advice about NRPf issues doubled during the pandemic, a 110% year-on-year increase⁴.

Citizens Advice commissioned research by The Migration Observatory at the University of Oxford. They found that the burden of NRPf restrictions falls disproportionately on people of colour – 82% of people helped with an NRPf issue by the charity over a 12-month period were Black, Asian or from another minority ethnic background. These are people already disproportionately impacted by the pandemic.

Those facing financial hardship face the impossible choice of losing their income or returning to work while ill, shielding, or living with someone who is shielding. Their health and that of their household is put at risk because they cannot access the welfare safety net.

Migrants from non-EEA countries are disproportionately likely to work in frontline roles, including in healthcare, care work and security jobs. Better support for people affected by these rules can support a safer easing of lockdown measures⁵.

Citizens Advice also noted that the temporary hardship of coronavirus could have devastating long-term consequences in the splitting up of families:

‘Those applying for leave to remain for spouses or family members are required to demonstrate a minimum income of £18,600 per annum. However, British citizens or settled persons who are made redundant or whose income as a self-employed person does not return to normal after 31 July may not be able to successfully renew their spouse or family member’s visa. This could mean families being separated because of a drop in income.’

 **110%** The year-on-year increase during the pandemic of the number of people contacting Citizens Advice about NRPf issues

Brexit

The NRPf Network has highlighted that changes to residence rights when free movement ends put European Economic Area (EEA) nationals at risk of losing access to employment and services⁶:

‘Following the UK’s departure from the European Union (EU) on 31 January 2020, it is now more pressing for EEA residents and their family members to secure their right to remain in the UK under the EU Settlement Scheme if they are intending to stay in the UK after 30 June 2021.’

Councils are raising awareness amongst affected residents, but it is important that all staff who are working with EEA nationals can identify and assist those who may need help to apply. Failure to do so may leave people in a position where they are unable to work, claim benefits or access other services⁷. The NRPf Network confirms that:

‘EEA nationals and their family members who are living in the UK by 31 December 2020 will have until 30 June 2021 to apply under the EU Settlement Scheme. EEA nationals who do not apply under the EU Settlement Scheme by 30 June 2021 are likely to become unlawfully present after that date.’

‘EEA nationals arriving in the UK on or after 1 January 2021 will be subject to UK immigration laws and will need to meet the same entry requirements as non-EEA nationals if they want to visit, work, study or join family in the UK.’

The Government has made funding available to organisations to help support people with their applications. For further information please read the *NRPf Factsheet* on ‘Helping European Economic Area (EEA) residents to secure status under the EU Settlement Scheme’ at <http://www.nrpfnetwork.org.uk/Documents/EU-Settlement-Scheme.pdf>.

 **82%** of people helped with an NRPf issue by Citizens Advice over a 12-month period were Black, Asian or from another minority ethnic background

Next steps

We hope that this publication serves as a useful guide in helping to better support carers who have NRPF during what it already a difficult time caring for a dying loved one.

We would like to see the palliative care sector as a whole more aware and better equipped to meet people's needs. We believe that this can be achieved by focusing attention on three fronts:

Individual level

At an individual level, we urge practitioners to increase their personal awareness and understanding of what it means to have NRPF. We hope that this will then lead to further questions and conversations in practice. Please think about:

- asking the right questions and recognising people's wider needs
- building networks locally, for example with migrant centres and hostels and
- signing up to the NRPF Network (<http://www.nrpfnetwork.org.uk/join/Pages/default.aspx>) and the Refugee Council (<https://www.refugeecouncil.org.uk/join-our-community/>) bulletins and updates, which provide a wealth of information.

Organisational level

At an organisational level, we would like to see all hospices recognising that this aspect of disadvantage is important and has far-reaching consequences. It is crucial to secure organisational buy-in and commitment to promoting the wellbeing of asylum seekers and refugees and, by extension, those with NRPF. We would like organisations to think about:

- how they can best support carers with NRPF
- whether any existing processes need to be adapted
- implementing training on NRPF for all staff, for example, the NRPF Network run a variety of courses (<http://www.nrpfnetwork.org.uk/training/Pages/default.aspx>) and
- establishing strategic relationships with partner organisations such as advocacy groups and migrant centres.

Data and literature

In terms of data and literature, we would like to see the information available strengthened significantly. There is an urgent need to:

- identify and record the number of people receiving hospice care who have NRPF
- research and assess how hospices can best support those with NRPF, especially carers and families, and
- amend and develop upon the existing plethora of literature so that there is information tailored to those with NRPF.

We will disseminate this publication widely, in addition to publishing a companion guide aimed specifically at migrant centres to familiarise them with hospice care. We will also explore the publication of the literature review that was undertaken to support this project in the hope that it encourages future research.

Resources

You may find these additional resources in this section helpful, the details of which were correct at the time of publication. You may also wish to record information about your local contacts, including:

- local authority NRPF teams
- local food banks
- closest migrant centres
- faith groups
- local charities and
- law centres.

Using search terms such as ‘no recourse to public funds’, ‘migrant’, ‘refugee’, and ‘asylum seeker’ along with your location may also help in finding local services available.

General

NRPF Network

A vital wealth of information provided by this network of local authorities and partner organisations focusing on the statutory response to migrants with care needs who have NRPF

<http://www.nrpfnetwork.org.uk/guidance/Pages/default.aspx>

Refugee Council

Provides crisis advice and practical support to refugees, including mental health counselling and supporting children and young people who arrive in the UK alone

<https://www.refugeecouncil.org.uk/information/resources/>

Praxis

Provides expert support to migrants and refugees in the UK, including immigration advice, housing and peer support groups

<https://www.praxis.org.uk/our-work>

The Salvation Army

Supports adult victims of modern slavery and human trafficking with legal advice and counselling as well as financial, employment and housing support

<https://www.salvationarmy.org.uk/modern-slavery/supporting-adult-victims>

Social Care Institute for Excellence

Good practice guide to support providers of social care services to work effectively with refugees and asylum seekers

<https://www.scie.org.uk/publications/guides/guide37-good-practice-in-social-care-with-refugees-and-asylum-seekers/>

Legal

Migrant & Refugee Children's Legal Unit

Provides specialist legal and policy support, based at Islington Law Centre in London

<https://miclu.org/>

The Law Society

An independent professional body for solicitors in England and Wales providing signposting to legal advice

<https://www.lawsociety.org.uk/public/for-public-visitors/using-a-solicitor/help-with-paying-legal-costs>

GOV.UK

Find a legal aid adviser

<https://find-legal-advice.justice.gov.uk/>

Physical

Docs Not Cops

A campaign group of NHS professionals and patients who believe that health is a right and not a privilege

<http://www.docsnocops.co.uk/>

Doctors of the World

Provides clinics and advocacy programmes in London that provide medical care, information and practical support to excluded people such as destitute migrants

<https://www.doctorsoftheworld.org.uk/our-work/uk/>

Social

Together with Migrant Children

Provides support primarily to migrant and refugee children, young people and families across the UK

<https://togethertomigrantchildren.org.uk/>

Notre Dame Refugee Centre

Assists refugees, asylum seekers, undocumented migrants and other human rights applicants who are in the UK seeking protection or who need other immigration advice

<https://www.notredamerc.org.uk/>

Hackney Migrant Centre

Supports refugees, asylum seekers and other migrants in need through the provision of free advice on immigration, welfare and health

<https://hackneymigrantcentre.org.uk/>

Project 17

Based at St Joseph's Hospice and seeks to end destitution among migrant children by working with families experiencing exceptional poverty to improve their access to local authority support

<https://www.project17.org.uk/>

Housing Justice

A collective of churches and other faith and community groups who provide housing support to help beat homelessness

<https://housingjustice.org.uk/>

Emotional

Nafsiyat Intercultural Therapy Centre

Offers therapies to people in 20 different languages and based in London

<https://www.nafsiyat.org.uk/>

Spiritual

Spiritual Gate

Provides information on the religious needs of people from all different faiths

<https://www.openingthespiritualgate.net/all-faiths/>

Bereavement

The Coroners' Society of England and Wales

Provides information on the legal requirements of repatriating a loved one aboard

<https://www.coronersociety.org.uk/>

Funeral Guide

Provides practical information on the repatriation of a loved one aboard

<https://www.funeralguide.co.uk/help-resources/arranging-a-funeral/repatriation-of-a-loved-one-for-a-funeral-abroad>

Glossary

Carer Support Needs Assessment Tool (CSNAT)

Forms part of an intervention to support carers of adults with long term life-limiting conditions. The tool itself has 14 domains (broad areas of support needs) in which carers commonly say they require support. It is integrated into a person-centred process of assessment and support that is practitioner facilitated, but carer led. Read more at <http://csnat.org>.

Change of Conditions (CoC)

Request for a change of conditions of leave granted on the basis of family or private life application.

Domestic Violence Rule (DVR)

An immigration rule which allows people who are living in the UK on a spouse or partner visa and are experiencing domestic violence to apply for Indefinite Leave to Remain.

Destitute Domestic Violence Concession (DDVC)

Support provided to destitute people who have no access to money to pay for essential living costs and are applying for Indefinite Leave to Remain under the Domestic Violence Rule. Successful DDVC applicants are granted three months' temporary leave to remain with access to public funds.

European Economic Area (EEA) national

A citizen of an EEA country, which comprises all of the countries of the European Union plus Iceland, Liechtenstein and Norway. Switzerland is not in the EEA, however following an agreement on 1 June 2002, Swiss nationals are generally treated the same as other EEA nationals.

Five-year route [to settlement]

A means to obtain settled status, whereby people who meet certain criteria can apply for two consecutive periods of two-and-a-half years' Limited Leave to Remain, after which they become eligible to apply for Indefinite Leave to Remain.

Further Leave to Remain (FLR)

A further period of Limited Leave to Remain.

Indefinite Leave to Remain (ILR)

A form of settlement available to non-EEA citizens which enables a person to live in the UK without any restrictions, and is the first step towards naturalisation and full citizenship.

Immigration Rules

A collection of immigration laws which state who is allowed to enter and stay in the UK, and under what conditions.

Limited Leave to Remain

Permission to stay and work in the UK granted for a restricted time period.

No recourse to public funds (NRPF)

A condition imposed on some migrants, due to their immigration status, limiting their access to mainstream benefits such as Universal Credit and Housing Benefit.

Ten-year route [to settlement]

A means to obtain settled status, whereby people who meet certain criteria are eligible to apply for Indefinite Leave to Remain after four periods of 30 months' Limited Leave to Remain.

References

- 1 The Migration Observatory at The University of Oxford (26 June 2020) <https://migrationobservatory.ox.ac.uk/resources/commentaries/between-a-rock-and-a-hard-place-the-covid-19-crisis-and-migrants-with-no-recourse-to-public-funds-nrpf>
- 2 Hospice UK: *Clinical and Care Support for Family and Carers* <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/family-and-carers>
- 3 Please note that the CSNAT is a copyrighted tool which requires a licence for its use. Visit the CSNAT website at <http://csnat.org/> for details about accessing it and the licensing process
- 4 Citizens Advice, June 2020 <https://www.citizensadvice.org.uk/about-us/how-citizens-advice-works/media/press-releases/citizens-advice-reveals-nearly-14m-have-no-access-to-welfare-safety-net/>
- 5 Ibid.
- 6 NRPF Network, March 2020 <http://www.nrpfnetwork.org.uk/News/Pages/EU-Settlement-Scheme-update2.aspx>
- 7 Ibid.

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- Claire Henry MBE who led the project on behalf of St Christopher's, Isabelle Cooper who undertook an extensive literature review and Kate Henry who pulled all the findings together into this publication.

For your notes

This page has been left blank for you to add your own notes, for example, contacts of your local migrant centres or sources of grant funding for people facing financial hardship. If your document is in PDF format, you will be able to click below to enter text. Once you have finished, re-save the document.

Sydenham site

51-59 Lawrie Park Road, Sydenham, London SE26 6DZ

Orpington site

Caritas House, Tregony Road, Orpington BR6 9XA

Telephone **020 8768 4500**

Email **info@stchristophers.org.uk**

www.stchristophers.org.uk

   **stchrishospice**

Registered charity 210667 registered with the Fundraising Regulator

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About St Christopher's

At St Christopher's Hospice our vision is of a world in which all dying people and those close to them have access to the care and support they need, when and wherever they need it.

We were founded in 1967 by Dame Cicely Saunders and, over 50 years later, her words still remain at the heart of everything we do: "You matter because you are you, and you matter until the last moment of your life."

Each person is unique and we tailor our care to meet social, emotional and spiritual needs, as well as manage physical symptoms. Last year we provided care and support to over 7,500 people across south east London, both at home and in the hospice.

We passionately believe that everyone should have access to the best care at the end of their lives and we exist to relieve suffering for anyone with a terminal or life-limiting illness. We provide bereavement support and spiritual help and guidance for patients, those close to them and our wider community.

We're actively involved in research around end of life care, training health and social care professionals and teaching students to become the palliative care experts of the future. Through our extensive education programme, we work with people across the world, to improve and develop hospice care.

About Hospice UK

Hospice UK is the national charity for hospice and palliative care. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it.

About St. James's Place Charitable Foundation

St. James's Place Charitable Foundation, founded in 1992, is the charitable arm of the St. James's Place Wealth Management Group.

The Foundation is at the heart of its business and aims to improve the quality of life for those people in need as a result of disability, disadvantage, physical or mental illness.

The Foundation seeks to achieve direct, tangible results from the support given.