

**Catholics for
AIDS Prevention
& Support**

*2016 Newsletter
World AIDS Day
December 1st*



CAPS

CAPS

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Front Cover Image: The Pieta Quilt was created by Penny Pendergast and was adopted as the logo for the Catholic AIDS Link charity (CAL) which was the 'parent' charity to CAPS. CAPS uses this quilt as a visual aid to prayer in our liturgies. It is displayed in the Church of the Immaculate Conception, Farm St., London around World AIDS Day.

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The views expressed in this magazine are those of the authors and do not necessarily represent the views of CAPS.

CAPS

Catholics for AIDS Prevention & Support

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Objectives

We are a network of catholics in Britain and Ireland promoting HIV prevention and support.

We aim to be a voice in the church for people living with HIV/AIDS and a catholic voice in the world of HIV/AIDS.

To promote education and prevention, treatment, care and relevant pastoral ministry for all those living with and affected by HIV/AIDS, particularly but not exclusively in the UK and Ireland.

To promote the practical, financial, emotional, spiritual, sacramental and pastoral needs of people living with or affected by HIV/AIDS and to develop appropriate responses.

To promote continuing reflection on all aspects of ethical, theological, and other challenges raised by HIV/AIDS, not least issues of social justice, through publication, seminars, and other relevant means.



Vincent Manning
Chairpersons’
message

Memory and
Anticipation

Another eventful year has passed and we look forward to another World AIDS Day on December 1st which as always, coincides with the start of Advent. It is an interesting juxtaposition – the remembering and looking back of World AIDS Day with the expectation and anticipation of Advent. As church we prepare to mark the moment that the Word became flesh and dwelt among us. So momentous an event in history, the birth of Jesus, that we celebrate and recall it annually. When I really think about it still ‘blows my mind’. It is so significant that we prepare with the four weeks of Advent, and

in a similar way we prepare through Lent to recall and celebrate Easter. The birth of Jesus, His passion and resurrection deserve our careful attention. If we are to celebrate these events in a way that is befitting; that holds more meaning than a party or even a treasured time with friends and family, our prayerful reflection is required, before we celebrate. We ponder, pray and remember, and prepare carefully, so that the reality of The Word made flesh and being with us now is, somehow, permitted to shape us in new ways. If we were to forget, then surely that possibility would be lost. Instead, we remember, we pay attention, we listen, in anticipation that the Spirit of Christ alive, will break in once more to the pattern of our daily living and our relationships.

Taking time to mark World AIDS Day is also an act of paying attention and remembering. And it is also more than just a time to recall the past - those whom we loved and lost; our own journeys through the AIDS years; our own experiences of passion and resurrection. It is an opportunity to consider the present realities, and pause, so that we might be open to the presence of Christ among us now living with HIV. To stop momentarily, in anticipation and expectation that the Holy Spirit may still move us, and shape us, and teach us, inspire us and call us to repentance, to renew us, through the lives and stories of people living with HIV and AIDS today.

This year we will also be remembering several of our members and supporters who have gone before us marked

with the sign of faith. If we allow them, they too will shape us and form us for the year ahead. They will live on in our memories, and importantly in our actions, as Christ lives on in you and me, if we pay attention, if we let Him.

Thank you for paying attention by reading this newsletter. Please share it with others. Thank you for your prayers, and your support and encouragement. We hope that you will find the articles, and the news of interest. I would also call your attention to the Diary Notes in the newsletter. Mass will be celebrated for World AIDS Day in London once more this year, on Dec. 1st, and we are grateful to the members of the Church at Farm Street who make this possible. There will also be a chance to view the AIDS Quilt panels at

venues around the capital. Finally, may you have a peaceful and blessed Advent, in anticipation of a Christmas full of joy, hope and love.



CAPS News Updates

CAPS receives major award from Public Health England (PHE)

As reported last year our short film ‘Love Tenderly Act Justly: Stories of HIV and Christianity’ (LTAJ) dir. Chris Loades, has continued to prove a useful resource in raising awareness. Not only useful for education in schools and parishes, it has also been helpful to many PLWH because ‘names’ the issues that they face, in the language of faith. As well as featuring

Christian PLWH describing their own experience, Church leaders including Rev. Canon Gideon Byamugisha, Very Rev. John Sherrington, CP, and Most Rev. Timothy Radcliffe, OP, offer messages of encouragement and hope to any person living with HIV, and challenge all Christians to become more welcoming and inclusive as Jesus was, to people on the margins of society and church.

In recognition of the success of this short film, and the importance of the issues raised for Public Health, CAPS has been awarded a grant from PHE through their ‘HIV Prevention Innovation Fund’ to develop the resource further. Our working title is LTAJ Phase II. The project was launched at Parliament on November 2nd 2016 and will be



CAPS Chair at Parliament Launch for LTAJ II with Prof. Kevin Fenton (Public Health England) and Jo Josh (Awards Panel Member)

completed by October 2017.

We will produce a further short film and several short clips that will address many of the issues. These will be ‘published’ online as an ‘open access’ resource. There are two intended audiences: first we think it will be helpful for Christian PLWH. It is remarkable that currently there is very little online that addresses people who are newly diagnosed or who are

worried about HIV, responsibly, in the language of faith. Like so many people today, the first port of call for information or to find help with anything, is often the internet. For Christian PLWH who may feel isolated it is important that they can access some positive and encouraging messages of support, especially in the time just after diagnosis. Secondly we hope the clips and the film will be used in parishes and schools to

start a conversation. To hold a workshop or put together a service for World AIDS Day, without the need to invite in an expert or pay for expensive training. As Gideon Byamugisha points out in our film, often it is not so much that Christian communities do not want to respond to PLWH, rather they are simply unsure how to do so. This resource will empower PLWH, and members of the clergy or laity, to raise some of the issues in their faith community, and begin to consider what God asks of us in response to the HIV pandemic.

Our revised target is to launch the project at a public event, and ‘go live’ in September 2017.

Positive Catholics Asylum Seekers

CAPS continues to

support several people seeking leave to remain in the UK. Most are Africans living with HIV who would find treatment and care impossible to access if they were returned to their countries of origin. In the current political climate, and the increased hostility to those who are immigrants, we have a special responsibility to do what we can to help reduce isolation and alienation. 4 people have received letters of support as part of their application for ‘leave to remain’ to the Home Office.

‘Ade’ is a very inoffensive quiet man. He has been a regular attender at the SWLF group for the past six years. For all of this time he has been awaiting a decision or making appeals regarding his leave to remain in the UK, where has lived for the

past 15 years. He did not show up for a couple of weeks. Our members became concerned. Eventually we learned that he had been ‘arrested’ and was being detained at an immigration and asylum detention centre. With the help of Jide Macaulay (our newly appointed sessional group support worker) Ade received a visit from friends in the group. He received vital support, including advocacy on his behalf regarding access to his medication which he had been deprived of. His lawyers were contacted. One of the issues was that he had no permanent place to live. He was subsequently released from detention and found temporary accommodation. The appeal process continues and Ade must wait for a final decision in his case.

Welfare reform

We have written several letters in support of members facing the government Work Capability Assessment, or assessments when transitioning from Disability Living Allowances to the new Personal Independence Payments. We cannot provide medical reports of course, but we can provide personal references where a person is clearly unfit to return to work. These take the form of descriptions of how long the person has been known to us, and their physical and mental capacity as we have observed them over time. These can be important especially for a person who may not be able to communicate their own health situation effectively under the pressure of an interview. As reported elsewhere, the welfare changes are impacting

many of our members negatively. Not only because benefits are often withdrawn or reduced, but because the process is stressful, and causes anxiety and illness.

Peer Support

Peer support remains the most important aspect of our ministry. Members continue to visit each other at home and in hospital, helping with groceries, transportation, providing simple fellowship, attention, and love. Approx. 155 adults of diverse ethnicity and sexual orientation who are PLWH have accessed support through attendance at our peer support groups and our retreat weekends. 18 children and young people also attended the weekends with a parent. Financial support has enabled the majority of retreat

weekend places to be offered to participants through bursaries and assistance with travel. Assistance with bus fares has also been provided to those on low incomes to attend the Positive Catholics group meetings in London and Manchester who would otherwise be unable to access support.

The South West London Fellowship peer support group has also continued to meet about 3 times each month. Over the past year the members have been offered extra support from Jide Macaulay and John Falcone who have both be paid by CAPS on a sessional temporary basis, to support our work. The members share food together at every meeting and have the opportunity to receive information from invited speakers who give inputs ranging

from 'Benefits Advice' to Healthy Eating' and other relevant topics that enhance health and well-being.

Sadly the Essex based 'Life Group' has stopped meeting. Local government contracts for the voluntary agency where the Life Group met changed, and 'in-kind' funding for the group ceased last year. In addition our main volunteer facilitator had a change of employment which meant that she was unable to continue leading the group. We are very grateful for the service she gave to others over several years.

CAPS takes on sessional support workers on a trial basis

Trustees agreed to employ 2 part time sessional workers from



Sessional Worker John Falcone in supervision with trustee Michael O'Halloran

October 2015 to late summer 2016, as a 'trial'. This turned out to be very fortuitous given that our Chair (and most active volunteer) was called away to look after his mother unexpectedly, from December 2015. Both Jide Macaulay and John Falcone have been of great support to our members, and their reports back to the Trustees have confirmed that the work of CAPS, and especially the peer support ministry does now deserve the support

of paid workers. Our volunteer led peer support model has been successful. In many ways it is because of this 'success' that trustees recognise that our work and ministry now requires some further professional (eg. paid) support. Not only because volunteering alone has obvious limitations, but also because our members, especially those who are most in need, deserve the best service that can be provided. We will be pursuing

options to fund paid workers for the years ahead who will support our volunteers in their important ministry of service for each other. The Trustees wish to publicly thank Jide and John for their commitment and dedication during 2016. (see article 'impacts of government cuts on page 12.)



In Memoriam

R.I.P. Stephen Portlock – CAPS Founding Member dies age 67.

CAPS founding member, Stephen Portlock, died on 18th September, after a long illness, aged 67. He had many visitors whilst in the hospice in the final months. Stephen had a full and interesting life.

He was an out Gay man and a convert to Catholicism. He worked in London in the 1970s and 1980s in social work. He had a long relationship with his former partner Alan, until he felt the call to religious life. In 1992 Stephen was with Alan when he died from AIDS on the feast day of St. Ignatius Loyola. 2 months later, on September 19th Stephen made his first profession and was accepted into the Society of Jesus, dressed in the suit that Alan had made by hand for him.

In 1995, Stephen was also diagnosed with HIV. His Jesuit Community accepted the news, and Stephen continued with his studies in philosophy and theology in preparation for ordination. No doubt there were challenges as not only Stephen but also the wider Jesuit

family came to understand what an HIV diagnosis means, 'in the family'. A few years later Stephen had the first of several heart attacks linked to the side effects of the HIV medication he was taking. He underwent heart bypass and other major follow up operations during 2002. Although Stephen was reluctant, he discontinued his preparations for ordination, and left Jesuit Community life in 2004 after nearly 15 years. Stephen maintained a great affection for his Jesuit brothers many of whom were frequent visitors to Stephen's home in Vauxhall, dropping by to share a gin and tonic, a meal, or to stay when visiting London.

During the 1980s Stephen was involved with the fore-runner to CAPS, Catholic AIDS Link. He was founding

member of the 'Soho Masses' offering a welcoming space for prayer to Catholics who were also Gay Lesbian Bisexual or Transgender, in the 1990s where he served as Sacristan and Eucharistic minister. In 2003 he was also a founding member of CAPS, and in 2004 he was co-facilitator for the very first meeting of Positive Catholics, in the basement of the Church of our Lady of the Assumption and St Gregory, near Piccadilly Circus. Stephen continued to host and attend the Positive Catholics meetings each month until he became too unwell to do so in 2014. Positive Catholics has had many 'homes' where we meet, but none so comfortable as the many years we spent meeting, eating and praying together at Stephen's home in Vauxhall. He was a generous host, preparing

food for all to share, with his signature bowl of tangerines and dark chocolate kit-kats always plentiful. Stephen liked his comfort. It was sometimes a sacrifice for him to attend our Retreats. Especially when we used to share bunk beds in dormitory style rooms at Bainesbury House, Downside Abbey. But he came, joyfully, in a spirit of service and actual solidarity with all the members of Positive Catholics. Without Stephen the Positive Catholics ministry would probably not exist today. He opened his home, and his generous heart, to Gay people, straight people, Africans, Irish, Latins. All were welcome. Stephen used to say that he was looking forward to this next stage on his journey, unsure about, yet slightly excited by, what Heaven would be

like. Surely he will have been welcomed already by our loving God, because Stephen was a good a faithful servant of the Gospel. A great friend to so many.

(There is a tribute to Stephen Portlock in the 2014 CAPS News available at <http://www.caps-uk.org/> on the 'About Us' section)



In Memoriam

Remembering 'Catherine'

Catherine was a Positive Catholics member for the past 10 years. She died aged 51 in September this year. We are not using her real name, as many of her friends were unaware of her status, and she never told her family. Catherine regularly attended our Positive Catholics Retreats. She made

many close friendships and had the freedom to 'be completely herself', without having to conceal her HIV status. She knew that she could 'relax', in the company of others who would accept her as she is, whilst not 'reducing' her to her HIV positive identity. We listened to the struggles she had with her health and HIV, and these were many. We also saw beyond HIV to her other beautiful qualities. Catherine suffered greatly with her physical health. She was disabled by meningitis, and in later years diagnosed with cancer(s). During her final months in a hospice, she wrote "I am waiting for death and willing it to come". Many of her friends in Positive Catholics visited Catherine there. She was often visited by our members during regular periods of hospitalisation. She

struggled with her HIV. Many times she would not take her medication despite knowing that this would leave her compromised immune system more vulnerable to opportunistic infections. She never quite managed to come to a place of 'acceptance'. Despite her suffering Catherine supported and encouraged other members of the Positive Catholics community. She had a genuine interest in listening to the stories of others. With a fierce intellect she enjoyed discussing theology and questions of faith. She was a match for anyone who liked a good debate. Her Catholic faith never left her, although she had many questions. At times she was impatient

and critical of Roman Catholicism in regard to the place of women. Perhaps this compelled her to go beyond boundaries, and she found her local Anglican Church a more conducive environment for Sunday worship and friendship in the last years of her life. Catherine remained a distinctively Catholic woman, who could laugh about, as well as challenge, aspects of the Roman Catholic tradition that she loved. She remained a valued and active member of the Positive Catholics community from the day she first tentatively joined us on Retreat, until the day she died. We trust that she is now finally at peace, free of pain, in heaven.



Impacts of government cuts and the restructuring of HIV Prevention, Care and Support.

CAPS has never received any kind of state funding to support our work outside of London. However, careful use of the funding that we did receive in London allowed us to get great value for money over the past several years, and extend our ministry to PLWH in other parts of the country, as well as providing for our Retreat weekends. (Of course this was also possible because of grants in cash and in kind that we received from our generous supporters). We warned

some years ago that changes in the commissioning of services, from national and regional health authority bodies to responsibility being located at local borough level, would impact upon our income, and more importantly upon services delivery more broadly. This year we have seen the changes take effect, and we are concerned that there has been a negative impact in many ways.

First, our income from providing peer support services in London has reduced from £18k in 2014-15 to just £6k in 2015-16. This is set to reduce further to £3k in the current year. Unlike many agencies in the voluntary sector, CAPS trustees have decided not cut any of the peer support group meetings that we run. However, we will need to secure other sources of funding

if we are to continue much beyond 2020.

Secondly, cuts to services delivered by local authorities has impacted negatively on services for PLWH. For example, HIV service Commissioners in Lambeth, Southwark and Lewisham (LSL) have recently announced that they will cease funding specialist advice and welfare services designed to support PLWH. Given that LSL remains the area of the country with the highest prevalence of HIV, this is a very perplexing and worrying development. LSL are justifying this decision by making the case that living with HIV is no longer an exceptional situation or health issue, and those requiring support can now access whatever they need within mainstream provision. We consider this a mistake,

based upon a false premise. Our experience tells us that whilst the medical prognosis is now much better than ever before, (if a person diagnosed adheres to medication), HIV still poses significant social, emotional, psychological, and spiritual challenges for those newly diagnosed and for those who are now entering 'old age' and have been living with HIV for 20 years or more. (see 'HIV is manageable! Manageable for whom?' p. 22)

Third, with reduced services for PLWH and the increased burden on mainstream services generally, at a time when they are also under pressure from cuts in budgets (everything from the Citizens Advice Bureaus to the local GP clinic) we are finding it harder to 'refer on', those members who

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need more specialist support than we can provide, with much confidence. This is especially the case for those who are in greatest need or with the most complex situations. People who are physically unwell; or have mental health problems; those struggling with debt; or facing eviction; or dealing with immigration issues; or worried about a cut to their benefits; or facing unjust treatment in the work place; or eviction. We are seeing people fall between the ‘cracks’ of one service and another. Some encounter well-meaning ‘mainstream’ workers often under pressure themselves, who simply lack an understanding of living with HIV and advise our members incorrectly; for others they simply find it too difficult to negotiate mainstream services

without more specialist support.

Fourth, government welfare reforms continue apace and many of our most vulnerable members are repeatedly required to undergo Dept. of Work and Pensions ‘Work Capability Assessments’. The additional changeover from Disability Living Allowances to the new Personal Independence Payments (PIP) appears to be a further opportunity for people’s circumstances and (dis)ability to be scrutinized with the concurrent threat of a reduction in their income. The pressure placed on some very vulnerable people, many of whom do not have the ability to fill out the necessary paperwork, should not be underestimated.

It may be that we are simply describing a break-down in state

structures and support systems that are affecting so many poor or marginalized groups in our society today. Across the board, it certainly seems that we are living in more punitive times than before. Structurally and systematically those who are already disadvantaged are more likely to encounter blame than understanding, and judgement before encouragement.

The impact on CAPS as a charity is that our Trustees are acutely aware that whilst our funding from the State is diminishing, the needs of those we seek to serve are increasing. The volunteer peer to peer model of ministry that we use, (in Christian terms a ‘disciple-servant’ model of ministry) whilst admirable, is creaking under the strains of both the increased needs of our

members and the pressures in society that we all experience to some extent.



Reverend Jide Macaulay

Religious Oppressors And the Oppressed.

“Do not repay evil for evil or abuse for abuse; but, on the contrary, repay with a blessing. It is for this that you were called—that you might inherit a blessing.” - 1 Peter 3:9

This Bible text reminded me of two incidences.

The first was at the AIDS 2016 conference in Durban South Africa which I attended. One Nigerian pastor at the Interfaith pre-conference used words and language that further



Deputy President Cyril Ramaphosa at AIDS 2016 Durban, South Africa.

discriminated against men who have sex with men. This is one of the key population groups being targeted in the fight against HIV discrimination. It was noted that the stigma against People Living with HIV (PLWHIV) is a contributing factor to the decline in HIV awareness and access to treatment. This pastor said “Homosexuals who are being

stigmatised should make themselves more visible so they can be known to the community and the church”. In Nigeria, homosexuality is unlawful, even attendance at a gay bar or club, or any public display of same sex attraction may result in a 10 year prison sentence. The overall societal and religious rhetoric against the Lesbians, Gays,

Bisexuals, Transgender, Intersex and Queer (LGBTIQ) people is a cause for alarm. When I had the opportunity I told the unkind pastor that those doing the stigmatizing ought to stop. Perhaps then those who felt ostracised and stigmatised might find solace in the church, which may include a holistic approach to pastoral care, support and counselling.

I don't believe homosexuality is a sin but I am convinced without any doubt that to stigmatise a gay man or a lesbian woman for their perceived or known sexual orientation and gender identity is ungodly.

The church is supposed to be a place of love, peace and kindness, not hate, war and fear.

The second experience was in Uganda, where homosexuality is also

outlawed. Over 300 LGBTIQ people faced police brutality in August this year. It was the occasion of a Beauty Pageant as part of Gay Pride celebrations. It was a completely peaceful event, like any other beauty pageant - very much like a fashion show. I was there and I saw the violence first hand. The head of police and over a dozen officers in uniform with firearms threatened the party goers because they do not fit within the heteronormative stereotype expected of the society to fulfill gender understanding. I was not arrested, I had special protection from the event security, but many others were. The violence and terror that I witnessed stays with me and has disturbed me. It reminds me, if any reminder is needed, just how dangerous it is to be a member of a sexual minority in a

country like Uganda. At the same time, it speaks to the courage of those who attended the event.

The background to the homophobia, and transphobia is linked with religious oppression and hate speech, carried out by extremist religious groups. So much so that the political minister of ethics, Reverend Simon Lokodo, (a former Roman Catholic priest) is asking for the killing of homosexuals and anyone else who doesn't fit the stereotype of heteronormativity. This is alarming when compared with the theological understanding of the love of God and passion of Christ for all humanity.

Christians need to learn from scriptures. You cannot terrorise the LGBTIQ communities, we are more religious and perfectly spiritually connected with our

sexual orientation, gender identity and expression as God intended for us.

Those who embody inclusive theology must continue to speak of and testify to the goodness of God. But those who are hateful to humanity especially towards LGBTIQ people, more often display rage and a burning anger.

Some churches may turn our families away from us and kick us out of their denominational congregations but they cannot kick Christ out of the LGBTIQ communities. He is present with us, and people continue to have their personal relationships with Jesus.

John the Baptist was a lone voice who condemned religious oppression, he was beheaded without justification. Jesus Christ

was hung on the tree to die like a common criminal. Thankfully the ignorance of His enemies could not keep him captive in the grave.

The violence against Lesbians, Gays, Bisexuals, Transgender and Intersex people is evil and ungodly and needs to STOP.

There are many congregations and thoughtful ministers who are openly, inclusive and welcoming. I appeal to PLWHIV and those who are LGBTIQ, and if you need pastoral care, counselling and support please contact us.

(Links to inclusive and welcoming church groups can be found on p. 34 of this newsletter)



Joyce lyamuya Catholic Conference on Disability - “Living Fully 2016”.

CAPS Trustee Joyce Lyamuya reports here on her attendance as a delegate at the Conference ‘Living Fully 2016: Disability, Culture and Faith - A Celebration’- Rome, 23-26 June 2016.

The meeting was to call and ask the church to be more inclusive to its members by remembering that we are all together the body of Christ. With our strength and weakness, abilities and disabilities, health and sickness, wealth and poor. Practice what the gospel teaches us and not create obstacles. Not strive to arrive to the end of our journey on



CAPS Poster for Conference on Disability.

our own, instead of all of us being there together by embracing, caring, helping and valuing each other. That will enable us reach there together. Which will please our Father in heaven as he would not like to lose any of his flock.

Running alone one will arrive faster and very weary but together will take more time but will

be stronger.

Many speeches were about the obstacles imposed to believers which hinders them to practice or get truly involved or feel at home in the church. Examples were given of children with learning disabilities who were hindered to receive their sacraments because they couldn't be instructed for them.

The conference showcased this by having the conference run in two different styles. One which was more appropriate for those who had limitation by using different methods of communication. Which used pictures, songs and acting and the second a traditional conference (speech).

The emphasis was about the church practicing what it preaches, and how Jesus lived and treated people. Embracing the Pope's call for the year of Mercy. Caring for one another, the poor, disadvantaged, sick, widows, stigmatised etc. There was a clear voice that came through: if the church does not need people who are different it's their loss. (This was from one of the participants).

The conference to me was a success. The only

thing I can highlight was it was preaching to the converted. There was not a big presence of the church religious (cardinals, bishops, priests and nuns). Of those who attended there was one bishop from the UK (Bishop Paul Hendricks of Southwark). I remember about four priests (two from UK and two from Rome) and a few nuns.

I introduced myself and explained that I was there on behalf of CAPS/Positive Catholics and explained what we do. I acknowledged the importance of the conference but noted that it was mostly people with physical/visible disability. I pointed out that we deal with a disability which is not visible and with stigma attached to it. So most people will be in church without being noticed and carry their

worries everyday without hope or help. It was just there as a silent killer inside their heart. Whenever one finds courage to speak out, they stop after hearing/understanding the perceptions in/of the church.

My conclusion is people are reaching out to the church but feel hindered and choked by the mechanism, administration and powers. But also we ask who is the church? To me it's all the believers who are Christ's disciples with its administration and power. One cannot move and let the body of Christ (the church) nourish without working together, caring for one another, encourage and listening to one another.



Vicki Morris

LTAJ an introduction

I am the new project manager for the 'Love Tenderly Act Justly' II (two). I am delighted to be leading this project over the next year as we produce a range of films and resources for people with Christian faith and living with HIV and their church and congregation.

Working freelance, I am also currently involved in the AIDS Memorial Quilt Conservation Partnership on behalf of Terrence Higgins Trust where I was London Operations Manager (Long Term Condition Management) for the past two years. I have changed direction in my work at this time because my family and I have relocated to Manchester after 20 years in London and before that,

Brighton. (see notices about the AIDS Quilt display for World AIDS Day in London churches on p. 34)

My career in the HIV sector started in 1991, as a 19 year old student volunteering as a home care volunteer, then home care support worker, for ACET Brighton (AIDS Care Education and Training). After punctuating my journey with a social work MSc and employment with Lewisham Social Services in statutory children's services, I spent 12 years with the wonderful charity - Positive Parenting and Children in South London, where I managed family support and social work services for families, children and young people living and affected by HIV. During this time I also managed 'The UK Family Project' (funded by Elton John AIDS

Foundation). We worked with Social Care in Belfast and Waverley Care to produce a range of resources for parents and professionals supporting families with HIV, across the UK. The aim was to reduce the impact that secrecy and HIV stigma has on children and young people affected by HIV across the UK. The needed field work was a profound experience for me. We brought together many isolated families and, indeed, isolated support workers. Families and workers were involved in residential and events where we all came together to share our experience and talk about the challenges of HIV in the family. This was an incredibly moving process through which everyone involved received support from others. We are still very proud of

what we produced together. Services developed which enable families and workers to feel more confident addressing issues about HIV and sex and relationships, within the family. (You can access reports about this project and a video on how to talk with children – see inset box on p.22.)

This experience as well as my time with Terrence Higgins Trust and managing their London HIV support services (Advice and Advocacy, Complementary Therapy, Counselling, Group work etc), has kept my passion alive to keep working and thinking about how to reduce stigma and its impact. Through a long relationship with CAPS, I have learned how important it is to address faith matters - from the provision of safe reflective spaces in the

Positive Catholics peer ministry, to ensuring that HIV commissioners of services understand the convergence of HIV and faith.

I am looking forward to working with CAPS on 'LTAJ II', and the creativity and connections that will come along. If you are interested in involvement please make contact: vicks@neovista.net



HIV, families and children

All the people that CAPS peer support ministry helps are members of a family. They are sons and daughters, sisters and brothers. Many are also parents with children who are growing up fast and are also living with HIV. The challenges for parents are many, and particularly complex.

How do you explain the regular visits to the hospital to your own children? When do you tell them that you are HIV positive? Should you tell them at all? What do you say to a child when mummy or daddy feels unwell, again? At what point do you disclose to your child that s/he is also living with HIV and how can you help them with the challenges as they grow up? How will you support them as they encounter the stigma? How will you help them manage their own health, their friendships, and maybe sexual relationships as they become young adults, responsibly? What are the feelings and emotions that arise for a mother or father who knows that the child they gave birth to and love so much, was given HIV along with the very gift of life itself? The list of questions is much longer.

We encounter these issues with the families that attend our support groups and residential weekends. Our members share their experiences and support each other in addressing these and all the other challenges.

In the previous article, Vicki Morris describes some of the work she has undertaken with families. CAPS has worked closely with Positive Parenting and Children (PPC) over many years, offering residential weekend places to some of the families that they have referred. We know that as well as offering families a simple break, and the children a few days of fun, these weekends have helped some couples to stay together by allowing them the time and space to learn from others. Essential 'adult time' together to talk about their hopes

and anxieties for their families can make all the difference, especially during a time of crisis. Sharing honestly in a supportive community of faith, and entrusting everything to our own parent – our own ‘mummy-daddy God’ – in prayer and through the sacraments, restores hope and strengthens our members who are facing the additional challenges of HIV in their family.



HIV is manageable? Manageable for whom?

If asked, most people over the age of 40 years old would say that the situation for people living with HIV today is so much better than it used to be, in so many ways. This assertion may be true, generally, but needs closer consideration. It is an assertion, or ‘narrative’

that is promoted by health Promotion Agencies, when we are told that HIV is now a manageable condition. Superficially this does not seem to be a contentious statement. However, it is not quite as simple as that.

This year alone, two members of the Positive Catholics community have died. Stephen has died in his mid 60s, and Catherine in her early 50s. Technically both of them died from

something other than HIV, and neither of them had that collection of opportunistic infections that used to define AIDS. Yet both of them had illness that was intrinsically associated with HIV. We could say that both of them died, at least in part from the complications of living with HIV.

It was similar in the 1980s and 1990. Many people who died of AIDS were not spoken of in those terms. Instead we often heard that they died from pneumonia, or heart failure. Often an attempt to save others the distress caused by knowing that their loved one had died of AIDS. Especially if the family had not known that their son or daughter had been living with HIV, this was certainly a pastorally sensitive thing to do. But, it also hid the truth of the matter.

People died from AIDS. The secrecy was maintained because AIDS was a terrifying disease that carried enormous social stigma. Families in grief might be spared the shame of public knowledge, that their loved one had AIDS.

In recent years, several of our members have died in their 40s and 50s, after prolonged periods of illness and hospitalisation. Lazarus Mungure, one of our Trustees has remarked: “It’s a reminder that we haven’t completely solved the issue of HIV”. This raises the question what exactly do we mean when we say that HIV is now a manageable condition? What is manageable? Manageable for whom?

The narrative of HIV as manageable, has been promoted by Health education agencies since the introduction of

anti-retroviral therapies, for two related reasons. Firstly the ‘manageable’ label is intended to reduce the fear and anxiety, associated previously with AIDS, but still prevalent today, so that more people will access HIV testing and those who need treatment will receive it before the onset of AIDS. As well as the obvious health benefits of early diagnosis for the individual patient, this is also a more cost effective outcome, not only for those infected but unaware, but also because of the potential to reduce cases of onward transmission. Secondly, the drive to ‘normalise’ HIV as just another physical condition like any other, is an attempt to reduce the stigma that is still associated with HIV.

I wonder if there are unintended effects that actually further

We recommend that you read the very interesting reports from The UK Family Project via the links below. These will help you to understand the challenges of HIV in families with children.

www.ppclondon.org.uk/wp-content/uploads/2014/09/familyProject.pdf

www.ppclondon.org.uk/resources/

www.chiva.org.uk/files/7514/3143/6628/livingwithHIV2.pdf

The final link will give access to practical guides and a series of short videos about HIV, children and adolescents

www.chiva.org.uk/resources/talking-children-about-hiv/

disadvantage people living with HIV and, rather than reducing or eliminating HIV stigma, add to it?

‘HIV as manageable’ reduces available support for PLWH

The support centres and agencies that provided counselling and other therapies for people living with HIV and AIDS in the 1990s, have all but disappeared. Those that remain provide much reduced services to PLWH. State funding has been redirected to medication.

Access to specialist HIV clinics and medical services are also being reduced. Patients with HIV are being redirected to access healthcare within the mainstream NHS sector, and the time allotted to individual consultations with an HIV specialist has

been routinely cut back, so that patients attending HIV clinics now do so to monitor blood counts, and little else. This leaves no room for a more ‘holistic’ approach to patient care. In short, it can be argued that what was once considered a fatal diagnosis with social, psychological and spiritual dimensions, is now reduced to a merely physiological condition within the NHS.

Something similar can be observed when it comes to testing people for HIV. Public resources are directed towards HIV prevention, often understood narrowly as HIV testing. This has taken precedence over support and care for those who are diagnosed already, (and may have lived with HIV for over 30 years in some cases), and those newly diagnosed. The ‘HIV as manageable’ message

results in a diminishing concern to address the social, psychological and spiritual needs of those who are diagnosed, as a matter of public policy.

It seems that ‘management’ of HIV in the UK, has been reduced to controlling the physical impact of HIV in the body, and the epidemiological impact in wider society.

“We haven’t completely solved the issue of HIV”

Scientific research has yet to discover what the effects of living with HIV over the longer term are. Early research indicates that people living with HIV will suffer higher rates of comorbidity and earlier death than in the general population. So we return to the question. What does manageable mean, and

for whom has HIV become manageable? Perhaps we can say that HIV has become manageable insofar as we can suppress the virus in the body for most patients, where diagnosis is timely and the person adheres to medication. We might also be able to say (in the future) that HIV as a public health concern has been brought down to manageable levels in society because of the success of HIV testing and HIV Health education campaigns. Current rates of HIV infection and new diagnosis leave this open to debate.

But this does not mean that HIV as a life event, has become manageable for the individual who is diagnosed. Nor does it mean that it has become manageable for the person who has lived with HIV for years, who may have side effects from

medication, or who bears the physical and psychological scars of AIDS defining illnesses. It may not be manageable for the woman who is depressed, and feels that each tablet to be taken only reminds her of the husband who abandoned her. Or the gay man who is reminded of his despised status in his family each time he visits the hospital. It may not be manageable for the African man who feels that he is being punished by God.

It is not ‘manageable’ for the asylum seeker who is frightened that enforced return to their own country might mean almost certain death. Not for those whose internalised stigma has never been addressed. Not for the isolated one, who feels unable to speak of their struggles with anyone else. Not for the man who carries the guilt of

those he infected.

The HIV as manageable message may obscure the fact that HIV is not in fact manageable for many people. Certainly not without help, time and understanding. In this way HIV as manageable, may obscure the reality, allow us to maintain some degree of denial, and by understating the challenges, we can become dismissive of the person who is living with HIV. Or simply, we become insensitive. Immune to their situations through ignorance.

Whilst the measure of manageability may be acceptable within the health services or government departments, and be justified in public health or medical terms, there is surely a higher standard which Christians understand, to which we are called and invited by the God

who wishes us to flourish.

Perhaps the 'HIV as manageable' message also allows the churches to continue to ignore the complexity of living with HIV. Perhaps we also find it comforting to explain that HIV is no longer the terrible death sentence that it once was. Perhaps we can confine HIV, and those living with HIV, to the clinic. It is a medical matter. We can avoid so much in silence. And so, the stigma which our theologues and ecclesial culture supports go unchallenged. Unless there is a Lazarus who speaks up to remind us that HIV is still present, if not quite visible in the Body of Christ.



UK AIDS Memorial Quilt

Victoria Morris

The UK AIDS Memorial Quilt displayed to mark World AIDS Day 2016

For the first time in 20 years the UK AIDS Memorial Quilt, an irreplaceable piece of international social history, telling the stories of people whose lives

were lost at the beginning of the AIDS epidemic, will be on public display.

St Paul's Cathedral

On Wednesday 23 November 2016, St Paul's Cathedral will host iconic panels of the UK AIDS Memorial Quilt to remember those lives lost and raise awareness of the HIV epidemic to younger generations.

These quilt panels will be laid across the floor

of St Paul's Cathedral underneath the dome. This will provide a stunning exhibition, especially from the whispering gallery, and will be the first time most of the quilt panels have been on public display together since 1994.

Visitors to St Paul's Cathedral will be able to view the quilts, and volunteers will be on hand to tell them more about the quilt and the people they commemorate. There will also be an opportunity for visitors to light candles to remember those we lost through HIV and AIDS. St Paul's Cathedral Education department will host a series of events with school children around the history of the quilt and the act of commemoration.

This rare opportunity is a chance to see the quilt, remember those lost, raise awareness of the epidemic to younger generations, and help a

coalition of charities find a permanent home for the UK quilt to ensure its preservation.

Opening times: 8.30am till 4.30pm (galleries open at 9.30am)

Entry: £16 online, £18 on the gate (adults), £14 online, £16 on the gate (concessions)

Gift Aid your admission and you will be entitled to 12 months free admission to the Cathedral at no additional cost to you. <https://www.stpauls.co.uk/tickets>

Quilt Trail

In order to make the quilt accessible to as many people as possible, on the weekend of Saturday 3 and Sunday 4 December, venues around London (including a number of churches and The Museum of Brands (London Lighthouse)) will host individual quilt panels. It is our hope that some people will view a

number of panels in different venues as you might if you were following an art trail.

All venues will be open to the public and accessible free of charge. A brochure with a map and list of the venues hosting the quilt panels can be downloaded here www.aidsquiltuk.org

About The UK AIDS Memorial Quilt

The AIDS Quilt is an irreplaceable piece of social history. It tells the stories of many of those lost in the early days of the HIV AIDS epidemic in the 80's and 90's. The quilt has been in storage for several years now and without proper conservation is in danger of deteriorating and being lost. Hence a number of charities have come forward to create the AIDS Memorial Quilt Conservation Partnership, to raise awareness of the quilt,



its importance in our history and to restore and conserve the quilt for generations to come. The quilt is a unique historical document.

In total there are 48 twelve foot by twelve foot panels, each comprising up to 8 smaller panels. Each panel is approximately 4m sq. Each individual panel c o m m e m o r a t e s someone who died of AIDS and has been lovingly made by their friends, lovers or family. The quilts represent approximately 384 people from all around the UK. Lives remembered include those of the writer, Bruce Chatwin; the artist/film maker Derek Jarman; the actors, Ian Charleson and Denham Elliot; gay rights activist, Mark Ashton and the photographer Robert Mapplethorpe. In addition emotive testimonials, photos, and

personal documents that tell the story behind the panel accompany many of the quilt panels.

The Quilt reminds us how far we've come in the fight against HIV – it no longer has to stop you living a long and healthy life - but there is still much to be done.



Vincent Manning

Ena, A woman of her generation. A personal reflection

Some years are more significant than others. I will always remember 2016, because in May, my mother Ena died. I was fortunate to be with her at the hour of her death. I thank God that I was able to stay with her for nearly six months in Ireland, as she prepared to leave this life. She is surely

with relatives and friends now in heaven. Embraced in Love.

Bridget Christina (Ena) Manning died aged 83 after a very full and eventful life. She is mother to 8 children, and many more grandchildren and great grandchildren. She came as an Irish immigrant to England, in the 60s, seeking work. She met and married Dan, and they remained together for the rest of their lives. As a young family, they encountered the anti-immigrant prejudices of that time. With two babies in arms, they endured homelessness in London. Eventually Dan found a steady job as a Prison Officer and with it came a family home. Ena was active organising community events and activities for the local children. Her door was always open to neighbours needing

an 'understanding ear'. A meal and a bed was often provided to strangers from near or far, whom my mother had come across somehow, somewhere. Many of these visitors remained life-long friends.

Living in a remote location without a car, the local prison was our Mass centre. Sunday Mass alongside men wearing the blue-greys of prison attire was normal for us. Despite being far from the Parish Church our parents still contributed to the life of the local church. Ena was catechist in chief. With the few other catholic kids on our estate she prepared us for the sacraments. Into our teenage years we had weekly 'catechism lessons' from our father. A decade of the Rosary each evening, together as a family, was

obligatory. We were raised as Irish Catholics in England, with the 'Sacred Heart of Jesus' at the centre of the home.

In the early 1980s Ena underwent an operation to remove a brain tumour, which left her severely disabled for the rest of her life. Remarkably, Dan was also diagnosed with a brain tumour shortly afterwards. Early retirement from employment followed. They returned to Ireland in the mid 80s where they flourished for the next three decades of their life together. Dan painted prolifically. Ena wrote short stories. As before, they got involved in the life of both community and parish.

It was the heart of our mother, always open, that left a lasting impression. Those who met her, liked her. She

had a capacity to listen without judging. To accept others as they are. Her willingness to work for the common good. Her own suffering never diminished her compassion-in-action for others, especially those considered the least - the despised person in the community, the prisoner, the person with mental health problems.

She was a woman of her generation – the kind of typical Irish Catholic mother that many of us will recognise. She was saddened and confused by many of the changes that she witnessed over her lifetime in society and in the Church. It was painful that some of her children and grandchildren had stopped going to church. The sexual abuse scandals caused immense inner turmoil. And she struggled to understand some of the

issues that my involvement with CAPS and HIV ministry, brought into her life. She never quite found the answer to 'why God had made gay people that way'.

On occasions she revealed a lingering sense of the shameful, when she asked me in whispered tones 'Is he gay?' or 'Do they know she is HIV positive?' Talk of HIV raises questions of sexual relationships, identity and behaviour - not subjects she would ever be comfortable discussing. Those were matters that she regarded as strictly private. The aversion to thinking (or talking) about matters sexual was ingrained in her from childhood. Somewhere deep inside, she still carried with her a residue of those moral judgments and the accompanying stigma, that resulted in pregnant girls being sent away to

the 'Magdalene Laundries' or young gay men being run out of town, in the Ireland of her youth. These things leave their mark on a person. My mother was a woman of her generation.

Nevertheless, Ena was a great supporter of CAPS. Any unresolved questions or uncomfortable feelings gave way to her understanding of the challenges that

people diagnosed with HIV face. She recognised that CAPS ministry is about extending welcome and friendship to people who are marginalised and often suffering. She got it. She always took an interest in what our members were doing. She would bring World AIDS Day to the attention of her Parish Priest in Ireland. Copies of CAPS News were left discreetly, at the back of the church



Bridget Christina (Ena) Manning

once a year. Along with our CAPS Prayer supporters group, she could be relied on to pray for particular people who were ill or facing some other crisis. She prayed for Catherine and Stephen and their families in the final weeks of her life.

Ena was an inspiring person. She gave a pretty good example of what it means to live as a Christian. Devoutly Irish Catholic, she knew the primacy of love over dogma. She encouraged others and practiced love in action. Her arms and home were opened, unconditionally, to hundreds of people of all kinds, from every nationality, young and old, gay and straight, and to people living with HIV. When doubt or anxiety afflicted her, she turned to God in prayer. Each night, when she could do no more, she

entrusted those she loved to the care of Jesus and Mary. And the next day she began again to do her part, to share love with others through ordinary acts of kindness.

Ena's open heart showed the love of the sacred heart of Jesus to me, and so many other people. I thank God for mothers like her.



Sr Gill Horsfield MMS

Sister Gill Horsfield is one of 650 Medical Mission Sisters in 19 nations trying to be present to others in the spirit of Jesus the Healer. Born and raised in England, Sr. Gill, a public health nurse and midwife, joined the Medical Mission Sisters at age 33, after serving as a lay missionary in Uganda. For nearly 20

years her Ministry was based in Korogocho. The Swahili name Korogocho means 'crowded shoulder to shoulder'. 160,000 desperately poor people live in this slum area on the edge of the main rubbish dump of Nairobi. Sr. Gill coordinated a programme providing community based health care for people with HIV/AIDS, she trained community health workers and pastoral workers from among the local people, working with the small Christian communities, with their help, and that of a counsellor and several nurses developing the programme to include a small hospice and a programme to support the children of the patients. Sr. Gill recalls: "Gradually a climate of compassion developed in the slum, families learnt how to care for their sick, and patients experienced

that they were loved by God and by us, enabling them to die in peace.”

Sister Gill age 83 is now a member of CAPS Prayer Support Group, praying for the Trustees and volunteers, the members of Positive Catholics, and all those who request prayer at a time of particular need.



Sr Gill Horsfield MMS Sing a song of resurrection

November is rather a remembering time, assisted by the darkness and the weather. My thoughts return predictably to Korogocho. We always celebrated Mass in our little classroom to remember our people who had died, all their names on newsprint around the walls. At the offertory all the health workers would put a small flower on the altar

for each of their patients who had died, saying their names. By the time they had finished, the whole altar was covered in flowers. We sang a resurrection song at the end of Mass, and afterwards I always reminded the health workers that those who were in heaven now will surely help us down here, still trying to do a slightly impossible job. We all felt very united with them then. I am sure that all those members of Positive Catholics who have gone to heaven will help you now.



Sr Gill Horsfield and friends outside the classroom in Korogocho

Getting Involved

Supporting CAPS

If you have felt encouraged in your faith, if you have been inspired by what you’ve read in this newsletter, please consider donating your time, your talent, or your financial support.

You can donate by contributing online through our secure PayPal connection: scroll down to the lower left side of our website, www.caps-uk.org. Or call / email us for information on setting up a direct debit.

You can also support us by signing up for ‘Give as You Live’, an online service that collects donations from over 4,000 retailers – sending a small percentage of your purchase’s value to the charity of your choice. Register for free at <http://give.as/>

charity/catholics-for-aids-prevention-and-support-caps or via www.giveasyoulive.com; search and select ‘Catholics for AIDS Prevention and Support’; and go shopping online with one of their registered retailers. At no cost to you, the website collects a donation from the retailer and sends it to CAPS.

If you have skills that you’re willing to share in marketing, research, policy writing, computing, press/media, finance, or fundraising, please contact Vincent at chair@caps-uk.org to arrange a conversation.

It is your generosity that allows CAPS and Positive Catholics to support and strengthen people who are in need.



Prayer resources

Sample Bidding Prayers for the Sunday before World AIDS Day (Dec 1st)

Thursday December 1st marks the 29th annual World AIDS Day. Let us remember all those living with HIV and AIDS. We pray for all those infected or affected by HIV all over the world. We pray for the doctors, nurses, scientists and carers who work for healing in this devastating pandemic. We ask God to bless the work of CAFOD and Caritas International, who serve the poor in the name of the Church. We pray for all those involved in the ‘Positive Catholics’ HIV ministry here in the UK. May God fill all of us with compassion and solidarity.

As we mark World AIDS Day on December 1st, let us pray for all people infected and affected by HIV and AIDS throughout the world. Let us pray that God’s justice and mercy will extend to all who suffer in this pandemic. Let us pray for doctors and nurses, and for all Christians who put God’s love into action. We remember too, the ministry of Catholics for AIDS Prevention and Support, here in the UK, praying especially for the members of the Positive Catholics HIV peer support communities in Britain.



Notices & Dates

World AIDS Day Thursday 1st December 2016

Remember to include prayers for all those affected by HIV and AIDS at Mass on Sunday 27th November. Use the prayers provided in this newsletter, or compose prayers of your own and share them by email with CAPS.

People living with HIV are often unseen and unheard. Our public prayers around World AIDS Day give us an opportunity to show our concern; they help us express solidarity with all those affected.

World AIDS Day events and services

Mass will be celebrated to mark world AIDS Day at The Church of the Immaculate Conception, 114 Mount Street, London, W1K 3AH on Thursday Dec. 1st at 6pm. ALL ARE WELCOME. Refreshments available afterwards in the parish hall.

An AIDS Quilt panel will also be on display along with the Catholic AIDS Memorial Book, quilt panel section and the embroidered 'Pieta' (featured on the front cover of CAPS News).

The UK AIDS Quilt will be displayed at St. Pauls Cathedral on Wednesday 23 November 2016. Quilt panels will be displayed in Churches to mark world AIDS Day. Please see article on p. 26 for full details.

Christian Communities Welcoming LGBT People

In London the RC Diocese of Westminster extends a special welcome to LGBT people at the Church of the Immaculate Conception, 114 Mount Street, London, W1K 3AH. Especially at the 17.30 Mass each 2nd and 4th Sunday of each month.

lgbtcatholicswestminster@gmail.com - www.lgbtcatholicswestminster.org

The 'House of Rainbow' also extends a welcome for LGBT Christian people

Email: info@houseofrainbow.org
Email: houseofrainbow@hotmail.com
Twitter: @houseofrainbow
Phone: +447507510357
Web: www.houseofrainbow.org

Making Your Church or Clinic a More Welcoming Place for People Living with HIV

Last year's 'All Are Welcome' Card was a great success and we are printing it again this year. It is an easy way to let people know that they have found a welcoming church. It is an easy way to raise awareness about HIV and faith in your congregation or your local clinic. Together with the THT 'Faith in Communities Project' we have designed this card to be ecumenical, and to offer the best possible points of contact.

We invite you to cut this page out. Share it with clergy or other church leaders. Have a discussion with your pastor or parish council about what it means to display this card at your church. Stick it on your church bulletin board. Bring it to the clinic or surgery. Let people know.

Below is some basic information about HIV that can help shape the discussion:

- There are more than 35 million people infected with HIV globally.
- Although medicines have become more available, only 32% of children and 41% of adults who are eligible, actually received HIV treatment in 2014. Millions remain in need of essential treatment, care and support, especially in Africa, a continent that cries out for justice.
- 108,000 people are infected with HIV in the UK.
- Approximately 50,000 are living with HIV in London. (Southwark Diocese has the highest resident number of people living with HIV.)
- An estimated 1 in 5 people living with HIV in the UK do not know that they are infected.
- We know that there are significant numbers of Catholics and Christians living with HIV.
- It is very likely that in your Parish there are people living with HIV, or families who have a member living with HIV.
- Catholics for AIDS Prevention and Support (CAPS) is the only national Christian response in the UK (Archbishop Peter Smith is a Patron).
- The 'Positive Catholics' ministry is the only national Christian pastoral ministry to people living with HIV in the UK.

Laminated copies are available by mail for a small donation to cover printing and packing. Other Positive Catholics materials are also available for download from our website. A single flier or poster might be the lifeline that someone needs.





All are welcome in this place

For faith sensitive HIV support:

Email: info@caps-uk.org

www.caps-uk.org

Phone: 07505 608 655

www.positivecatholics.com

For advice and support:

Contact THT Direct: 0808 802 1221

For training, education and testing in your church:

Contact Terrence Higgins Trust's

Faith and Communities Project

Phone: 0207 812 1807

Email: marcy.madzikanda@tht.org.uk

