

Positive Now and the All-Ireland  
Network of People Living with HIV

# HIV

## Our Responsibilities

An invitation to conversation, to research,  
to understanding, and to action



**PositiveNow**  
All-Ireland Network

# HIV

## Our Responsibilities

Formed in 2010, **Positive Now** is a group of diverse people living with HIV who are working to build and enable an all-Ireland network of people living with HIV, and to ensure that the voices of HIV positive people are represented at all levels. We endeavour to constantly challenge HIV related stigma and discrimination.



Positive Now  
53 Parnell Square West  
Dublin 1, Ireland

T +353 (0)1 873 3799  
F +353 (0)1 873 3174  
[www.positivenow.ie](http://www.positivenow.ie)

# Background to HIV: Our Responsibilities

*Positive Now, members of the All-Ireland Network of People Living with HIV, and Dr Aislinn O'Donnell co-researched and co-wrote this document. Dr Aislinn O'Donnell also helped to facilitate the focus groups from which the document emerged.*

This document is a living document and an invitation to conversation, to research, to understanding, and to action. The research was not on people living with HIV. It is research with and by a diverse group of people living with HIV that emerged through a process of discussion, investigation, and co-construction of knowledge; it involved a careful process of editing in order to ensure that we had said

what we wanted to say in our own voice. This document represents that voice and analysis. It speaks from our experiences, observations, and reflections. We think of research as a collaborative process, and we value the process as well as the product. We want to invite others to help deepen and develop the diverse ways of understanding the relationship between HIV and responsibility.

# Thanks and Acknowledgements

*We would firstly like to thank Dr Aislinn O'Donnell; we are very grateful for her sensitive, warm, yet challenging approach to teasing out our voices and for making us think critically about ourselves as citizens.*

We would also like to thank the staff of Dublin AIDS Alliance for all their support in helping us to develop and grow **Positive Now** and the **All-Ireland Network of People Living with HIV**.

Most of all, we would like to thank the **MAC AIDS Fund** staff whose support has been evident from our inception. We are very grateful for all you have done for us and for others living with HIV in Ireland. We especially want to give a shout

out to all the **MAC Cosmetics** staff in Ireland – past and present – whose enthusiasm and creativity in their day to day work has resulted in so many good things for people living with HIV around the world.

**This document is dedicated to Thom 'The Diceman' McGinty, Pat Tierney, Linda Reed, and Noel Walsh, HIV activists who each left a unique stamp on the history of HIV in Ireland.**

# Introduction to HIV: Our Responsibilities

*“We must seek to build together an active, inclusive citizenship; based on participation, equality, respect for all and the flowering of creativity in all its forms. A confident people is our hope, a people at ease with itself, a people that grasps the deep meaning of the proverb ‘ní neart go cur le chéile’ – our strength lies in our common weal – our social solidarity.”*

**PRESIDENT MICHAEL D. HIGGINS**

Three decades after the first campaigns to raise awareness about AIDS, many people living with HIV still feel silenced, isolated, judged, fearful, and excluded. Three decades after the first campaigns to raise awareness about HIV, people still hold prejudices that stem from their ignorance and lack of education about HIV. This document invites all of us to reflect on our own responsibilities in relation to HIV and to people living with HIV. It is estimated by the **European Centre for Disease Prevention and Control** that around 30 % of people living with HIV in Europe are unaware of their status. Many people still don't understand that being HIV positive

is not the same thing as having AIDS (Acquired Immune Deficiency Syndrome), and that it does not mean that one's condition will necessarily progress to AIDS. Still all of us, whether living with HIV or not, want to belong and be treated as equal members of our society.

People who are HIV negative or who do not know their HIV status may say 'But HIV has nothing to do with us!' But HIV has touched all of our lives over the last thirty years. Living in a democracy gives us rights, and with those rights come responsibilities to each other. We are not isolated individuals. All humans are born into a community and live together

in a society; our lives affect one another. We have responsibilities to others by virtue of being born into a society, by virtue of being who we are. And the feeling of belonging to a society brings with it both rewards and responsibilities. Our collective responsibility as members of society means taking responsibility for what we do and who we are. It involves recognising the ways in which beliefs, attitudes, actions and values, and even indifference and ignorance, can hurt others. People living with HIV each want to be treated as a human being, just like any other human being. People living with HIV want to be part of communities, contribute to society, and be treated equally and fairly, just like anyone else. People living with HIV do not want to be seen as victims. Society must come to understand that people living with HIV are not a threat.

If our democracy is to be genuinely inclusive, it must find ways of welcoming and supporting the voice

of those who feel silenced or who are fearful of speaking openly, as well as those who feel that they have no right to speak because they are different from the 'norm'. If our democracy is to be participatory, our institutions must be inclusive and ensure that the voices of Irish society in all its diversity are listened to and heard. If our democracy is to be understanding and open, we must stop moralising and begin empathising.

Nobody wants to have to hide who they are from others, or to feel ashamed for simply existing. Irish institutions have to face a legacy of silencing and rendering voiceless many of our society, in particular those most vulnerable. Nobody wants to be reduced to a category or a label. We each want to be seen, recognised and valued for who we are, in all our complexity, whilst acknowledging that we have responsibilities to others who also wish to be valued in turn. We are equal members of society.

*This living document is an invitation to all of us to reflect on our responsibilities in relation to HIV. It represents the voices of many people living with HIV in Ireland today and it seeks to begin a conversation. It looks at the question of responsibilities from four perspectives: society, institutions, professionals, and people living with HIV.*

# SOCIETY & HIV

## Why is society responsible?

*People with HIV can live with HIV. What we can't live with are other people's negative reactions, or the lack of knowledge that fuels prejudice and discrimination.*

Equality legislation protects us, but we also want to be trusted, accepted, and treated equally in everyday life. We are ordinary people who happen to be HIV positive. People living with HIV come from every walk of life. We are your neighbours, your colleagues, your friends, and your family. We want to be part of our shared society,

to be open about our status and to be listened to and heard. Ask yourself whether you inadvertently silence people living with HIV? You may not mean to, but you may perpetuate silence and marginalise people because of your values, beliefs, attitudes or ignorance about HIV.

## What can society do to become more responsible?

- |   |  |   |   |
|---|--|---|---|
| ● | <b>Stop labelling:</b> See the human being and not the status.   | ● | <b>Stop being scared:</b> There is no reason to be fearful. Find out the facts. Talk openly, and be compassionate.  |
| ● | <b>Stop moralising:</b> It doesn't help us and it wouldn't happen with any other illness. It makes us fearful of disclosing our status, and it creates shame and worries about rejection.  | ● | <b>Be empathetic:</b> Think about how you would feel if you had to live with a serious health condition.  |
| ● | <b>Don't make us hide:</b> It is really hard to hide our status from people we love, from our employers and from wider society. It is stressful and that doesn't help our health. Allow us to be honest, and to disclose in our own time and in our own way. | ● | <b>Offer support:</b> It is not only people living with HIV who live in silence. Friends and family can also find it hard to cope.  |
| ● | <b>Get educated:</b> Know how transmission occurs and get rid of the myths. Know that lots of people who are HIV positive don't yet know it so you should always be careful about what you say about HIV.  | ● | <b>Create networks of friendship and support:</b> Sometimes people are isolated geographically or come from small villages. Realise how hard it is for anyone who feels like he or she is going through something difficult alone. Support people.    |
| ● | <b>Find out the facts:</b> Know that the risk of HIV transmission by people living with HIV who are keeping well, who are on medication, and who have a low viral load, is minimal.  | ● | <b>Accept people:</b> Like everyone else, we want to be accepted for who we are. If society is more open, it will be easier for people living with HIV and their families to be open and to get the support they need.                                |
| ● | <b>Be responsible:</b> Transmission usually involves two people who have consented to engage in an activity. Take care of your own sexual health and don't depend on people to disclose their HIV positive status. Use condoms correctly.                    | ● | <b>Treat us like you would treat anyone else.</b> We are your fellow human beings.  |
| ● | <b>Be careful:</b> Don't share needles.  | ● | <b>Remember that there are ups and downs with HIV.</b> Much of the time it won't be obvious. This may be the case for many years. Sometimes people need more care. Sometimes people are fine. Be flexible and understand the nature of the condition. |

# INSTITUTIONS & HIV

*Institutions are human creations for human beings. They are supposed to make life easier by helping us to live together, by developing our capacities as human beings, and by supporting us in times of need.*

Making sure that our institutions serve all people is a priority. For that to happen people need to have a voice, and that voice needs to be heard. Inclusive institutions welcome people speaking in their own ways and are careful to make sure that a dominant ethos doesn't silence minorities and other voices.

All institutions in Irish society have a responsibility both in respect of HIV and to people living with HIV because people living with HIV are members of all of the institutions in Irish society.

## What helps?

- **Storytelling:** Leaflets are fine, information is important but people's stories cultivate real understanding and empathy. The face to face living presence of another human being is powerful. Be it the school, the workplace, or the hospital, find ways of bringing people into your institutions so that they can tell their stories.
- **Holistic approach:** Institutions need to care for the body, mind, and spirit of the person. All of these elements will be important in us getting well and keeping well. Develop holistic approaches that work with all of these dimensions. Learn from good practice in other countries.
- **Support staff:** People who are professionals are asked to respond with care and sensitivity to people. They too need to be treated well and to feel valued by their institutions. They need to have their work acknowledged within institutions. Likewise, those with whom professionals interact need to be sensitive and to remember that it is not 'just a job' and that professionals are often doing their best in difficult conditions. Nobody is perfect.

# What can individual institutions do?

## Educational Institutions

●	Help children and students understand HIV and understand the modes of transmission.
●	Educate them about empathy, tolerance, and care for people living with HIV, and our responsibilities to one another as human beings.
●	Think about whether your ethos and practices mean that people moralise and judge people with HIV.
●	Provide meaningful and honest relationship and sexuality education to minimise risk. Don't let ideology or ethos get in the way of keeping young people informed, safe, and well.
●	Create an environment in which people can ask questions.
●	Educate teachers and lecturers so that they are aware of, and sensitive to, issues relating to HIV and the lived experiences of people who are HIV positive.
●	Remind educators that they also have a responsibility to educate themselves about HIV and related issues.
●	Examine why your application forms may inquire about someone's HIV status bearing in mind the Equal Status Act 2000 and Equality Act 2004.

## Health Institutions

■	Ensure that <b>all</b> staff, not only medical staff, are educated about HIV. This reduces the risk of discrimination and prejudice.
■	Make sure that everyone understands the importance of Universal Precautions.
■	Make sure that proper systems and processes are in place to ensure confidentiality.
■	Ensure confidentiality and trust, and ensure that people who live with HIV know that you will prioritise their confidentiality. This is important be it in small villages or big cities.
■	Remember all patients in your institution are human beings. Don't talk about us as if we were invisible. Talk <b>with</b> us.
■	Support medical students in building relationships. Relationships are the foundation for care.
■	Communicate to staff that they should ask patients if they would like to share their thoughts or experiences.
■	Be sensitive to how difficult it can be for people if they have been newly diagnosed. Help staff to understand the need to be patient and understanding.

# What can individual institutions do?

## Health Institutions (Continued)

■	Be informed. Make sure staff understand the facts. Remember the role of staff extends beyond diagnosis to support. Make sure all staff have access to the phone numbers, information and supports that people will need, particularly just after diagnosis.
■	Remember that patients may be more educated about their condition than staff. Listen.
■	Learn from other countries about good practice in reducing the risk of HIV transmission. This could include consumption rooms to keep people safe when injecting and sharps bins in toilets and public spaces to minimise the risk of needlestick injuries.

## Employers

●	The Employment Equality Act and the Equal Status Act (2000 and 2004) means that you can't discriminate against your employees on any of the nine grounds (Gender, Civil status, Family status, Sexual orientation, Religion, Age, Disability (which includes HIV according to the Equality Authority), Race, or Membership of the Traveller community). Understand your obligations under this legislation.
●	Be supportive and be proactive in relation to the needs of your employee.
●	Create a safe and open environment so that staff can be open with you.
●	Understand that people living with HIV will have ups and downs health-wise and try to be flexible.
●	Remember your employees want to contribute and want to work. Make sure all employees know that they will be supported and not judged if they are HIV positive. This will encourage people to stay working rather than leave work in order to hide their condition.

# What can individual institutions do?

## Employers (Continued)

●	Educate management and human resources by bringing in people who are living with HIV to tell their stories.
●	Develop peer-learning models so that all employees can share information and knowledge about HIV.
●	Communicate the importance of education, acceptance and care in order to combat prejudice, stigma, discrimination, and ignorance.

## Prisons

■	Be honest whether the living conditions of the system really provide sufficient care for wards of the State who are living with HIV.
■	Prioritise decent sanitary conditions. Provide easy accessibility to condoms and install needle exchanges, as is the case in prisons in other countries, to ensure safe injecting and to ensure people do not get re-infected.
■	Think about the health environment in your prison and the potential risks of infection for someone living with HIV. Find out how your institution can minimise or eliminate these risks.
■	Make sure processes and procedures are in place to ensure confidentiality.
■	Reflect upon the impact of sharing cells for those who are HIV positive, both in terms of well-being and in terms of privacy.
■	Put in place processes to ensure adequate access to medication and health care.
■	Remember deprivation of freedom is the punishment. Ensure the well-being of prisoners, since many have multiple needs.

# What can individual institutions do?

## Prisons (Continued)

■	Make sure prisoners are educated about HIV and the risks of transmission.
■	Ensure confidential counselling is available to all prisoners who are HIV positive as stress and anxiety can impact upon health.
■	Make sure food preparation facilities meet rigorous health standards.
■	Ensure that prison staff are well-educated about HIV issues, informed about modes of transmission, and understand the importance of confidentiality.
■	Ask yourselves whether prisons are increasing the risk of HIV transmission or reducing it? What responsibility do Irish prisons have to Irish society in respect of transmission? What responsibility do Irish prisons have to prisoners living with HIV?

## Department of Social Protection (Welfare)

●	Be sensitive to the reasons why somebody may be evasive when questioned about health matters.
●	Respect his or her right to not disclose his or her HIV status.
●	Understand that people living with HIV may be well at certain times and less well at other times. Ensure that the welfare system supports both the right to work and the right to sick leave.
●	Take everyone on a case by case basis.
●	Remember it takes time to adjust to being diagnosed HIV positive.
●	Remember that people living with HIV may have both mental health and physical health needs.



# What can individual institutions do?

## Judiciary

■	Make sure that the decisions made are impartial rather than a reflection of personal prejudice. It is important to be educated and highly informed about HIV and the modes of transmission of HIV.
■	Ensure that judgements do not reward people for their ignorance about HIV. An individual's ignorance about modes of transmission should not result in significant compensation for them.
■	Understand how difficult it can be for someone who has been diagnosed with HIV and who is living with HIV.
■	Remember that most transmission takes place through consensual activity. Both parties need to take responsibility. Not knowing or not asking is no reason for not practicing safer sex or safer injecting.
■	Use sensitive language when speaking about HIV.
■	Know when the issue of HIV is relevant or not relevant to a person's case. A person's HIV status can often be brought up in court unnecessarily.

## Religious Institutions

●	Ask how your teachings are affecting the lives of people living with HIV. Do they contribute to prejudice and discrimination? Do they support openness, care, and education?
●	Reflect on how attitudes toward sexuality may affect the ability of people to speak openly about HIV and safer sex.
●	Ask whether your teachings are making it difficult for people to disclose their status.
●	Be honest about whether you are facing reality and facing humanity, or putting ideas and ideals before living people.
●	Don't judge and don't pre-judge. It increases the likelihood of shame, silence, and the fear of rejection. This means people aren't informed, aren't open, and this itself increases the risk of transmission.
●	Be compassionate, but don't pity and patronise.

# What can individual institutions do?

## Direct Provision and Services for Asylum Seekers

■	Remember that people don't choose to become asylum seekers.	■	Think about the lived experiences of families, couples, and single people living in Direct Provision, including the lack of privacy. This can be particularly difficult for people living with HIV who do not wish to disclose their status.
■	Create institutions and living environments that humanise rather than dehumanise people.	■	A healthy diet is important for people living with HIV. Afford people the opportunity and resources to cook for themselves and their family. This is also important for children to feel that they are part of a home environment.
■	Afford people dignity and the capacity for autonomy to take care of their families. Seeking asylum is hard. Living with HIV is made much more difficult by the stress, anxiety, and lack of privacy entailed in the Direct Provision system.	■	Reflect upon the impact of isolation and exclusion from the wider life of society when one is in the Direct Provision system, living on €19.10 a week. This is compounded by the isolation, stigma and discrimination often felt by people living with HIV.
■	Remember that meaningful work and education are important for well-being. Think about the impact on people, including people living with HIV, of living in an institutional context, often for many years. Develop opportunities for us to contribute to society and to share our skills and knowledge.	■	Remember that policies of dispersal can isolate people further, in particular those in need of medical care and support because of their HIV status.
■	Ask yourselves about the similarities between current forms of Direct Provision and the prison system. Asylum seekers have committed no crime.		

# What can individual institutions do?

## Direct Provision and Services for Asylum Seekers (Continued)

- Consider the effects of the privatisation of the system that prioritises efficiency and profit over the well-being of people, many of whom have already experienced significant trauma.
- For those funding Direct Provision and managing the asylum process, ask whether the State is fulfilling the duty of care and obligations to uphold the human rights of those seeking asylum by virtue of Ireland being a signatory of the Universal Declaration of Human Rights. Think about the impact of failures in this respect for those in the system, in particular those living with HIV and children affected by HIV.
- Create the opportunity for people seeking asylum to have a voice in the system. People living with HIV may have particular requirements to ensure privacy, health, and mental well-being.
- People have the right to seek asylum. Make sure that the conditions in which they live during this process are humane and humanising. Conditions that lead to further stress, anxiety, and marginalisation will have effects upon the health and well-being of people living with HIV.

## Gardaí

- Ensure that you are well educated and informed about modes of transmission. Being fearful from ignorance is not acceptable.
- Ask yourselves whether your fears around HIV transmission are grounded in fact.
- Don't perpetuate myths and stigma through your own fears and prejudices.
- Understand that there is no legal obligation for a person to disclose his or her HIV status.
- Protect the confidentiality of a person who is living with HIV.
- Make sure that people have access to their HIV medication if they are in custody.
- Learn how to support someone who may have fears about having been infected with HIV. You can play a vital role at this time.

# What can individual institutions do?

## Media

- Make sure presenters and opinion formers in the media understand the facts about HIV.
- Find a balance between the right to have an opinion and the propagation of ideas that lead to prejudice, misinformation, and discrimination. Not all opinions are equally valid.
- Try to include images and stories of ordinary people leading ordinary lives, despite their HIV positive status. This is more truthful and helps to break down the myths and fears around HIV.
- Remember that sensationalising stories and creating fear destroys lives. Don't take a one-sided view.
- You have a significant responsibility in terms of people's well-being and you can create more openness about HIV. All the good work being done to break down prejudice can be easily destroyed by the desire to sell papers or make a publicity splash.
- Don't put an increase in profits before people's lives.
- Be truthful, be honest, and have journalistic integrity.

## Organisations working with Sex Workers

- Work to create conditions that empower people involved in sex work and that keep everyone safe. Driving sex work underground can lead to violence and further marginalisation and isolation.
- Ensure that all sex workers, including people living with HIV, are supported in developing skills to negotiate and promote safer sex.
- Ensure access to free condoms.
- Listen to the diverse voices of those involved in sex work and develop strategies and policies that reflect this diversity.
- Work to combat the marginalisation and social exclusion of people involved in sex work. Stress and anxiety are made more acute by discrimination so reflect on strategies and approaches that can keep everyone well, including people living with HIV.

# PROFESSIONALS

*This is a set of suggestions for people who have professional relationships with people living with HIV. It is primarily for health practitioners but a number of points are important for professionals working in other institutional settings to note.*

Although many of the points are covered in the 'Institutions' section, it should be underlined once more that the work of professionals is appreciated and the best approach

for responding to, and being responsible in respect of, HIV involves sharing ideas, working together, and ensuring that everyone feels treated with respect and valued.

■	Know that it is ok to ask questions and make conversation, but don't be intrusive. Don't ask about how we contracted the virus.	■	Don't judge and don't moralise. It won't help and it makes it much more difficult for us to be honest with you.
■	Being diagnosed is like starting a new life. Offer comfort and care, no matter what our circumstances are.	■	Listen, be understanding, and don't fake it. We will understand if you don't have all the answers.
■	You are responsible to know the facts; however also be open to listening to the knowledge that we may have. We may have more knowledge than you.	■	Stay informed on HIV issues and trends. Engage in continuous professional development.
■	Do take care if you are substituting for another GP that you do not inadvertently look surprised or shocked when you learn of the status of your patient. This is upsetting to us.	■	Remember HIV is a long term condition. We are on a journey together and so everyone needs a voice.
■	Make sure that you have access to the information about the different kinds of support that the person will need, in particular people who are newly diagnosed.	■	Please recognise that HIV is not like other chronic illnesses such as diabetes or high blood pressure. It is infectious and it brings its own unique difficulties.
■	Don't push people who are HIV positive into the last appointment slot of the day because you think it will reduce the risk of HIV transmission to other patients. The onus is on you to exercise Universal Precautions not for us to disclose our status.		

# PEOPLE LIVING WITH HIV

*People living with HIV have responsibilities. We take our responsibilities seriously, but we emphasise that responsibilities in respect of HIV are shared.*

The onus of responsibility does not only lie with us. Consenting adults need to be informed and take responsibility for their own actions. We want to take the responsibility of working with institutions, professionals, and wider society to create an atmosphere of openness, solidarity, care and support in our society.

Being a citizen means taking responsibility for the lives of others. We want to play our part in creating an Ireland that acknowledges and values the diversity of the people living here today. We also know that we each have responsibilities in respect of HIV.

●	<b>Find out:</b> We all need to know our status, be it HIV positive or HIV negative. Everyone has a status, one way or the other. Knowing keeps us safe and well and keeps others safe.	●	<b>Be safe:</b> Practice safer sex. This is to protect others and to ensure that we don't get re-infected with a second strain of the virus or other STI's.
●	<b>Get educated:</b> Do your best to stay healthy, take medication, and know what will interfere with your health and well-being. Be aware that taking your medication every day and minding your health keeps our viral low down and minimises the risk of us transmitting the virus to others.	●	<b>Be responsible:</b> Even if someone wants to be infected (it happens), don't agree to try to infect that person.
●	<b>Be honest:</b> Health practitioners need to know your status to be able to offer appropriate care. It is often helpful for pharmacists to know as they will be able to let you know if certain medications will interfere with your HIV medications and vice versa. No one needs to tell anyone else until they are ready.	●	<b>Don't share needles:</b> Plan so that you can ensure that you have clean needles. Dispose of needles safely and protect communities.
●	<b>Remember your responsibilities to your child:</b> Women who are pregnant need to make sure that their unborn child is not at risk of becoming infected with HIV. They need to adhere to anti-viral medication during the pregnancy.	●	<b>Support each other:</b> Develop buddy systems and peer networks. This can be really important when people are newly diagnosed, but it is also important to have people around who know what you are going through. Don't gossip or spread rumours about another person's HIV status. Don't disclose another person's HIV status. This adds to our own isolation and furthers the stigmatisation of HIV. Respect each other's confidentiality.
●	<b>Don't misuse your status:</b> It is important not to misuse a HIV positive status in order to intimidate, manipulate, or threaten others. This does damage to every one of us who is living with HIV.	●	<b>Remember your rights:</b> Disclosure is not, and should not be, mandatory. People have to be able to tell people in their own time and in their own way. Think of who you might tell and why you are telling them.
		●	<b>Look for solidarity:</b> Everyone needs support and acceptance, HIV positive or not. Remember there are lots of people who are accepting. Being open can diminish the sense of isolation, loneliness and fear that people living with HIV can experience.

- **Be understanding:** Difficult as it can be at times, try to understand the situations, difficulties and worries of professionals and of institutions, and strive to treat people decently, with civility, and with patience.
- **Don't let your imagination take over:** Deal with the reality of people and the reality of the situation. Often people are a lot more understanding and supportive than we might think.
- **Develop relationships:** Work with society, institutions and professionals to educate and to humanise institutions and society, and remind professionals that the professional relationship is a **relationship**. This extends beyond the issue of HIV to what it means to be a human being and a citizen. Remember that professionals can have limitations in relation to what they can do or achieve for you.
- **Tell stories:** For those of us who are ready, tell stories to help deepen understanding and develop a sense of empathy. It is a great educational tool and it breaks down barriers. Everyone's story is the story of a life, not of a status.
- **Be patient:** Sometimes people don't know what to say or do, and part of the task of people who are living with HIV is to educate others and help them understand. It makes life easier for everyone.

- **Don't stop working just because you are worried about your HIV status becoming known:** Everyone needs to feel that they are contributing and belong to society. If you aren't working, don't let your status and your fear get in the way of you looking for work. But take time out when you are not well enough to work or to look for work.
- **Think about others:** Being HIV positive is hard for friends and family too. Taking care of each other also means taking care of ourselves.
- **Remember to look for help when you need it:** No one is ever alone. There are people to talk to, there are professionals to offer support, and there are other people who will understand what you are going through.
- **Make informed choices about your health:** For example, when to start or change medication, but also realise that you have a right to autonomy in relation to making decisions about your health and well-being.

# Future Conversations

*Talking about HIV is not easy. Sometimes people don't know what to say because they don't have much knowledge, so space needs to be made for people to ask questions without being worried that they will sound silly.*

Sometimes talking about HIV is too easy as it can be more convenient to point the finger at others and moralise, rather than to reflect on one's own life, the risks that all humans take, and the ways in which our lifestyles can damage our own well-being and that of others. So let's start to talk about our relationship to risk, and what is acceptable and unacceptable. Let's think about our responsibilities in relation to public health more broadly, and what it would mean to see public health as

both a public good and something for which we may all be responsible for as citizens and human beings. Of course, sometimes we just don't want to talk about certain things that we know might cause conflict, or which may push us to challenge our own beliefs, practices, and values. Doing that means holding up a mirror to ourselves. But that can often give us more clarity and a capacity to be more open to the perspectives of others.

# Future Conversations

*This document is a living document asking us to begin difficult conversations and honest conversations with each other, regardless of our HIV status. It is a stimulus for thought and conversation; it is not a finished piece.*

It raises lots of questions like: What are the things that professionals may want to say, but won't because they feel they need to be seen as non-judgemental? What are the things that people living with HIV want to say, but won't? What are our expectations of people living with HIV in relation to being supported? Have these expectations changed with the advances in medication? Can we find ways of having honest and respectful conversations with each other as equals beyond client-professional relationships, in particular about issues that we tend to sweep under the carpet? Being challenged can be really useful.

This living document invites all of us to continue this conversation. We know that different people will have different positions. The only thing that we ask is to find a way of continuing the conversation that keeps at its heart respect for one another, whoever we are. We can all try to understand what it is like to walk in someone else's shoes without necessarily agreeing with all that he or she says or does. And we might see the world and ourselves differently if we can listen to each other's perspectives and stories.

Check out [www.positivenow.ie](http://www.positivenow.ie) or write to us if you are interested in participating in further events and conversations about these questions.



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