

Tom Hayes -
beyondpositive

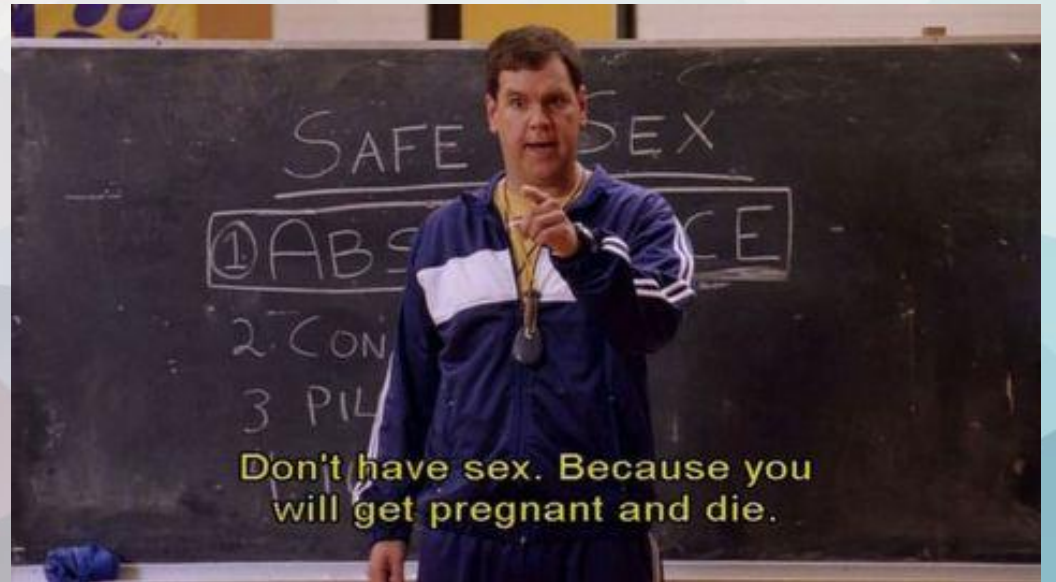
From diagnosis to treatment advisor

Disclosures

- Grants: None
- Honoraria for speaking from: ViiV Healthcare UK, Gilead Sciences, MSD UK, GSK
- Trustee, Saving Lives UK Charity

“Any homosexuals apart from Thomas?”

- Born 1985
- Went to “good” Church of England schools
- Came out at 13
- “Sex education”
- Moved to London
- Redundant & Divorced in 2010
- Moved to Birmingham 2011



“What?! @#*&! Don’t have sex!”

- Attended a Birmingham GUM clinic for routine check - Aug 2011
- Went on two week holiday next day
- Ignored calls from unknown number
- Eventually answered
- Handled *badly* to say the least
- Attended on my return
- Handled *badly* again
- Attended terrifying (for me) support group
- Avoided follow up



“They’re nice people really”

- Lucky enough to have a positive friend
- Spent an evening talking me through:
 - What happens at clinic
 - How treatment works
 - How to get my point across / get my own way
- Saw that this version of informal peer support worked for me
- Realised I wanted to do the same – but on a wider scale



Let the training begin!

- 2012: Not much in way of peer-to-peer training available
- Dr Steve Taylor saw potential
 - Attended his 'HIV & Hepatitis Resistance & Pharmacology' workshops
 - Aimed at HCPs so I attended twice.
- Joined the MyHIV team as an online peer support worker
- Read every article I could find on aidsmap & i-base
- Attended every scientific symposium I could get to
- Started writing conference & paper reports for various journals
- Set up an informal Whatsapp group for me to contact a select group of HCPs for advice when needed

What I did then / What I do now

- Whilst living in Birmingham I offered informal peer support to the HIV teams at HEFT.
 - Be present on days with multiple new starters
 - Asked to be present when specific patients were in
 - Signposted the teams to resources via Whatsapp.
- Now I live in London most of my support is done online
 - One on one chats with people who find me organically, or directed by HCPs I know.
 - Informal advice at GMFA events for positive MSM which I facilitate
 - Still help out the Birmingham teams where I can

What I did then / What I do now

- Introduction to the clinic & team on first visit
- Tips for making most of your clinic visits
- Sign-posting to online and local resources
- Re-explaining
 - What all the terminology mean
 - How ART works & why important to take on time
 - U=U
- Chaperoning (both testing & on-going care)
- Advocating for patients (switching / side effects / etc.)
- Social issues (financial / housing / benefits)
- Making tea & coffee

“Yeah, that one, the blue one”

- Top issues:
 - Patients unaware of the medications they’re on
 - Patients not feeling confident to bring up problems with HCPs – especially embarrassing ones.
 - Isolation / lack of support outside clinic
- Top questions:
 - Interactions (prescribed / OTC / recreational)
 - Side effects (HIV meds or not?)
 - Other illnesses (HIV / side effects or not?)
 - U=U
 - Switching



Why patients don't bring up issues

- Embarrassment factor:
 - Imagine talking to a HCP you've never met about issues such as:
 - Sexual dysfunction
 - Bloating / Loose bowels
 - Appearance
- Lack of correct language:
 - English not first language
 - Unaware of 'technical term'
- "Doctor knows best" – the infallibility of HCPs
- "I guess I'll put up with it"
 - I don't deserve any better
 - It's not serious enough to bother the HCP

Tips to encourage discussion

- Peer workers in waiting area
- Pre-appointment checklists
 - Either email / SMS / in waiting room
- Use open language
 - YES/NO vs How are...
- Offer chaperoning if possible
- Encourage patients to ask questions
- Review notes before appointment
- Suggest side effect diaries
- Enable/encourage patients to own their data
- Be aware of your/colleagues' reactions & micro-reactions



Video by KaydenGrayXXX – kindly supplied for educational use 02/10/2019 – full video at [YouTube.com/KaydenG](#)

I am but one, very busy, homosexual

- How to support your peer support worker / community treatment advisors:
 - Give us access to **resources** – but don't reinvent the wheel
 - Get us into **training...**
It doesn't need to be specifically P2P training, give us a little credit
 - Give us **space to talk freely** to you – at a team meeting, or patient forum
 - Realise our **limits**
 - Treat us with **respect** – we may not be a HCP, but we're not idiots either
 - Where possible look to **hire & pay us** (see Bloomsbury Clinic)
 - Don't **overwork** us
 - Sometimes your most promising patients won't be interested.

Great FREE resources

- HIV i-base
 - Printed and PDF guides on EVERY topic with illustrations.
- NAM aidsmap
 - A wealth of online guides from both the simple to the technical
- PositiveEast & NAZ Project
 - Great location for BAME targeted info & support in multiple languages
- GMFA
 - Resources and events targeted specifically at MSM with/affected by HIV
- THT MyHIV
 - Confidential online forums and chat for people living with HIV

Thank you