Tablet tales – myths, misconceptions and other patient questions

UK Community Advisory Board Workshop
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Taking meds and adherence

• If I tell the truth about missing tablets every so often *will I get a telling off*, or another one of those chats about adherence aids that I have heard 50 times already? Maybe I will just lie and say I have taken them every day on time...

• Why can't I stop HIV meds for the weekend ... I like to forget about HIV and have fun. . . Can't hurt, surely?

• What happens *if I vomit* after taking my meds? Do I need to take another dose (*interestingly leaflets give different time frames for retaking*)

• Can I crush my tablets if I find them hard to swallow?

• Do I have to have food with my meds ... because these days most ARV meds for most people do not come with food restrictions. And what do you mean by food with meds?... A full meal?
Drug interactions

- Drug interactions, eg with integrase inhibitors - the difference between magnesium supplements and magnesium stearate, which exists in many supplements (including the meds themselves).
- Managing other illnesses that need other meds: there have been several times where I’ve had to tell the GP that I can’t use something...it affects my ART... they didn't check first, just prescribed (but it is getting better...I'm training my regular GP now...)
- What about any potential interactions with meds and supplements not mentioned on the Liverpool interaction website? What are the most common and what symptoms should we look out for?
Side effects

• What are the most common side effects - how does the long-term use of medications affect internal organs eg liver, kidneys, heart?
• Is bone thinning a side effect of some meds? Which?
• Do meds impact my mood and emotional health? Can my skin and body temperature change as a result of taking medications?
• Do HIV medications affect my sleep? I have tried three different meds but still wake up several times a night with strange dreams.
• Being a small woman, I feel like I get more side effects from medications, so I only take half a dose. Why don't we look at different dosing options based on size/weight, to reduce unwanted side effects?
• Why do some people get blips in their viral load despite taking their meds?
Weight gain

- I've heard that using ART's makes you put on weight?
- When will health care professionals stop blaming patients for weight gain, and citing diet, when actually there is more evidence emerging that medication is causing weight gain, especially in women.
- When will social prescribing be included in patient care to help those of us dealing with weight gain?
Travelling with meds

• I have heard that you have to carry a letter from your doctor with you saying what your meds are for if you carry them in hand luggage in UK airports?

• I travel overseas...but I hide my HIV meds, because that might disclose my status and some countries don't let people with HIV enter. Or they don't like the ARVs and confiscate them.

• What happens if I travel to a country in a different time zone?... Do I still need to take medication based on UK time?
Meds and recreational drugs or alcohol

- How do my meds interact with recreational drugs?
- I have heard that drinking alcohol will lower my CD4 count
Over to you . . . any more questions?
Use your app or raise your hand to ask your question

Thanks!